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ABSTRACT

The philosophical and practical aspects of the retarded citizen's need for a home in the community are discussed in 14 author contributed chapters dealing with people and communities, rights and independence, home and community, services and communities, and action and advocacy. Chapters cover the following topics: "Community Life and Individual Needs" (C. Cherington); "Listen! Let Us Speak" (R. Audette); "Whom Do We Call Retarded?" (G. Dybwad); "The Retarded Citizen and the Law" (D. Freedman); "The Goal of Independence" (J. Howse); "A Parent Speaks" and "What Is A Home?" (L. Moise); "Creating Community Homes" (N. Newman); "A System of Services" (S. Gelman); "One Service System at Work" (B. Lensink); "Service Delivery in Rural Areas" (D. Popp); "Outreach in Urban Areas" (T. Graf); "New Directions for Volunteers" (R. Perske); "The Politics of Community Action" (T. Holland), and a summary of fundamental principles, goals and new directions (R. Freedman). (CL)

June 75

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NEW NEIGHBORS

THE RETARDED CITIZEN IN QUEST OF A HOME

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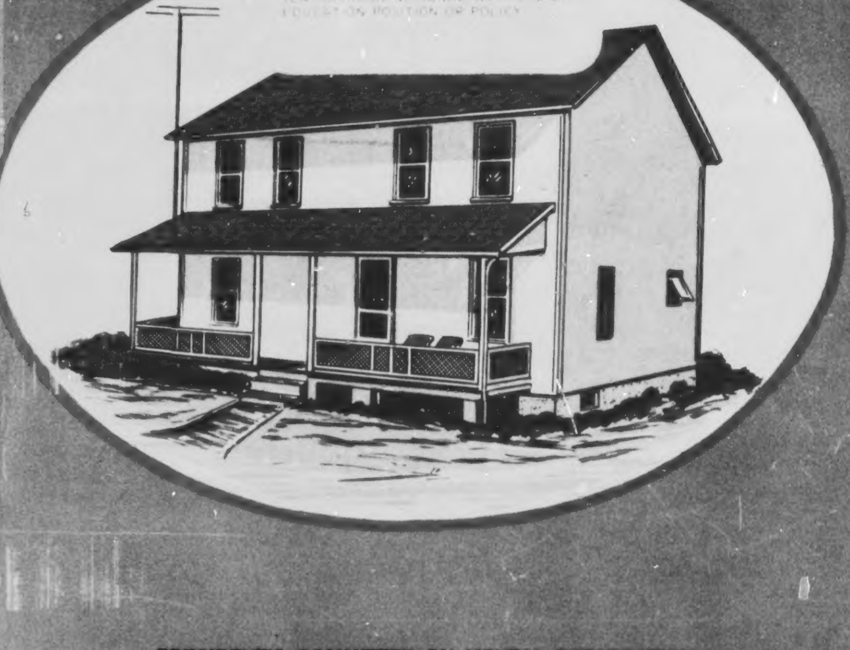

PRESIDENT'S COMMITTEE ON MENTAL RETARDATION
WASHINGTON, D.C. 20201
1974

NEW NEIGHBORS

THE RETARDED CITIZEN IN QUEST OF A HOME

Edited by
Carolyn Cherington and Gunnar Dybwad

The Florence Heller Graduate School for
Advanced Studies in Social Welfare
Brandeis University

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PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

The President's Committee on Mental Retardation was established by Executive Order of the President in 1966.

The Committee is composed of a chairman, 21 citizens members and five ex-officio members, appointed by the President to advise him on what is being done for the mentally retarded; to recommend Federal action where needed; to promote coordination and cooperation among public and private agencies; to stimulate individual and group action; and to promote public understanding of the mentally retarded.

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PREFACE

By Beth Stephens

Member President's Committee on Mental Retardation

"New Neighbors: Retarded Citizens in Quest of a Home" is one important element in the effort of the President's Committee on Mental Retardation to facilitate and accelerate the transition to an era in which retarded citizens will be able to obtain a full spectrum of services in their home communities.

It does not cover all such services. Several essential services are or will be the subject of other reports by the President's Committee. For example, we have previously dealt with screening and assessment of young children at developmental risk in a publication so titled, and with the need to provide appropriate special education without unfair labeling and isolation of handicapped students, in the publications "Six-Hour Retarded Child" and "Very Special Child." Early intervention to correct defects in infants and young children will be treated in a report on a conference recently held under the Committee's sponsorship.

This book discusses philosophical and practical aspects of the retarded citizen's need for a home in the community, but does not purport to be a complete "how-to-do-it" manual. The Committee has in preparation a publication on community residential alternatives that will be a useful supplement to this volume for persons engaged in establishing group homes, and also calls to their attention "The Right to Choose," published by the National Association for Retarded Citizens.

The Committee does believe that the present book offers guidelines to all fair-minded Americans for welcoming their "new neighbors."

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The Editors wish to acknowledge valuable editorial guidance provided by Dr. Burton Blatt, Professor and Director, Division of Special Education and Rehabilitation, Syracuse University; Hugh Lafave, M.D., Director, Eleanor Roosevelt Developmental Center, New York State Department of Mental Hygiene; and Robert Perske, Executive Director, Greater Omaha Association for Retarded Children.

To John Mercer we are indebted for invaluable editorial services.

Finally, our thanks go to Allen Menefee, our Project Officer, and to other members of the staff of the President's Committee on Mental Retardation for their patience and their helpfulness.

Carolyn Cherington
Gunnar Dybwad

LIST OF CONTRIBUTORS

Robert Audette
Director of the Bureau of Program Development and Evaluation, Massachusetts Division of Special Education, Department of Education, Boston, Massachusetts.

Carolyn Cherington
Project Director for Developmental Disabilities, "The Roles and Functions of State Planning Systems," Brandeis University, Waltham, Massachusetts.

Gunnar Dybwad
Gingold Professor of Human Development, Florence Heller Graduate School for Advanced Studies in Social Welfare, Brandeis University, Waltham, Massachusetts.

Donald Freedman
An attorney and Associate Director, Massachusetts Bureau of Developmental Disabilities, Executive Office for Administration and Finance, Boston, Massachusetts.

Ruth Freedman
A social science consultant and an author of *Serving Children with Special Needs*, U. S. Office of Child Development, 1973, and of *A Day Care Guide for Administrators, Teachers and Parents*, MIT Press, 1973.

Sheldon Gelman
Assistant Professor of Sociology, Pennsylvania State University, State College, Pennsylvania.

Thomas Graf
Executive Director of the Atlanta Association for Retarded Children, Atlanta, Georgia.

Thomas Holland
Director of the Human Services Design Laboratory, Case Western Reserve University, Cleveland, Ohio.

Jennifer Howse
Administrator of the Developmental Disabilities Program, Florida Division of Retardation, Department of Health and Rehabilitative Services, Tallahassee, Florida.

Brian Lensink
Director, Douglas County Office of Human Services, Omaha, Nebraska.

Lotte Moise
Member of the Project Policy Board, Sonoma County Citizen Advocacy Program, Fort Bragg, California.

Nathan Newman
Fresno, California is co-author of *Community Placement of the Mentally Retarded*, Charles C. Thomas, 1973.

Robert Perske
Executive Director of the Greater Omaha Association for Retarded Children, Omaha, Nebraska.

Dennis Popp
Coordinator of Developmental Disabilities Services, Kansas Division of Mental Health and Retardation, Department of Social and Rehabilitation Services, Topeka, Kansas.

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INTRODUCTION

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These terms, the watchwords of our current thinking about mental retardation, connote that retarded people have entitlements to an existence and a style of life which approximate reality as the rest of us experience it. By their existence, the terms also imply that retarded people are usually treated as abnormal, static, dependent, and unfeeling. Because of a strong belief that retarded people are somehow less capable than they really are, and, above all, less human than others, society has built "special" environments for them. Too often, what makes these environments "special" is primarily their abnormal, static, dependent, and unfeeling quality. In the present quest for "normalization" and other ideals, we are working for community alternatives, for one of the most "special" environments for mentally retarded persons has been the institution, away from the community. If these community alternatives are to be any more truly human and "normal" than the institutional alternative and some community alternatives of the past, we must begin by thinking about what living in the community means to us.

In the past, few of us even considered the idea of community whether our community was a large urban neighborhood or a farming village. Most of us have always lived in the community. Therefore, only when something goes wrong with us or with the community itself do we examine our living in it.

Community living challenges the field of mental retardation because so few retarded people have lived successfully in the community.

In recent years, more people have begun thinking about what living in the community means because things do seem to have "gone wrong." During the post-War years of relative peace, riots, racial conflicts, rising crime rates, overpopulation, pollution, and the decadence of physical environments in American communities forced us to examine more carefully our tastes and preferences about community life. Under particular stress in these times has been our ability to get along with people different from ourselves. Our tastes and preferences have surfaced as prejudices. People are moving away from those who are threateningly different. By using exclusionary tactics, many of these people aim to build more homogeneous communities and thereby to fulfill their quest for peace and meaning. Those excluded because of their race and poverty are left to dwell in decaying physical environments. For their part, they are demanding community control and power over their territory, whether in rural areas of the midwest and southwest or in the urban neighborhoods throughout the nation. Finally, interest is growing in communal forms of life, and particularly younger people are attempting to create new communities which conform more closely to their sense of values. People are more actively searching for a way of living in the community at a time when "community" seemed to be a lost ideal.

With community life painted in these hues, it may seem ill-advised to talk about exposing retarded people to the tastes and preferences of others. Should we try to build community alternatives in every community, including those decaying and so full of trouble? Should we challenge the will of people who seem so sensitive to differences from themselves? Should we, in short, expose retarded people to the risks of community life? The authors of this monograph clearly believe we should. Not only should retarded people be entitled to the "dignity of risk," but they should not be considered so different from others. We are not "exposing" a deviant group to the test of reality. We are trying to enable human beings to live as human beings. And that means that some retarded people will live in decaying neighborhoods because that is home. Retarded people will live with us, wherever we are, because we are people, like them.

PART 1

PEOPLE AND COMMUNITIES

CHAPTER I

COMMUNITY LIFE AND INDIVIDUAL NEEDS

by Carolyn Cherington

INTRODUCTION: INDIVIDUAL AND COMMUNITY

The new terminology in mental retardation—"normalization" and "developmental model," in particular—imply significant changes in our thinking about the nature of retarded people. Since this monograph is directed toward people in communities, we must consider the nature of community living. If we really are to enable "normalization," we must discuss the needs of retarded people in reference to normal lifestyles in communities. To create a special set of needs concepts because retarded people are in some sense special would be to create a conceptual institution of sorts, an island of concepts which, if actively used, would isolate retarded people just as much as have our physical institutions and special programs in the past.

The introductory remarks to the monograph presented the belief that most people yearn and strive for lives which give them peace and a sense of meaning through work or some other productive activity. How is a person, any person, enabled to live peacefully and productively in his community? The answers to such a broad question will undoubtedly vary widely with the individual characteristics of that person, as well as with features of his particular community. What enables one person to live peacefully and productively in his community might not enable another to live well in that community. Similarly, the same factors might not enable a person to live in any other community as well as he does in the one he is accustomed to.

What, then, are some common factors about a person and his community which enable that person to live well? The person, if he is to be self-sufficient, must have the skills basic to survival—to provide for his shelter, food, and physical maintenance. Self-sufficiency in our world also suggests comfortable social interaction, a family, a job, an education and recreation. These are *universal human needs.* If a person is incapable of complete self-sufficiency—as is true of many of us, retarded or not—someone else must help him either to acquire survival skills or to meet those universal needs. At some time, most of us get help from friends and family in these areas of life; most of us get help, too, from public entities such as educational systems; and many of us get special help in areas that cause us difficulty throughout our lives.

What about the community? Perhaps the "quality of life" of the community allows a person to live well there. "Quality of life indicators" include opportunity for individual status achievement; equality of opportunity for both sexes of all racial and economic groups; living conditions; agricultural and technological development; economic status; education, health, and welfare; and state and local government characteristics.[1] But many people can live well in communities which would be rated low by these indicators. An individual would probably not choose to move away from a community where he felt at home, no matter how poorly the community fared on objective ratings of its quality.

Unfortunately, no studies exist to tell us what makes a community good for one person and not good for another. Clearly, however, a critical factor, a factor implicit in many of the "quality of life indicators," is the extent to which the community enables the individual to develop and to maintain himself there. Underlying this factor are the attitudes of that community toward its individual members. Many sociologists would suggest that if the community is homogeneous and an individual conforms to community expectations, that person will probably be able to live well there. Independent factors cannot be systematically extracted from the nature of communities and the nature of individuals to tell us how to find the best "match."[2] In addition to the fact that individual preferences vary despite the quality of life, as objectively rated, there is the reality that the community itself reflects its membership. In some sense, then, an interaction between community and individual characteristics will predict harmony or discord.

Let us now say that the person in question is and functions as one who is "retarded." What would enable him to live well in his community? First, he would have to able to meet his universal human needs. He would need to develop survival skills or obtain resources from outside his own means to meet his needs for shelter, food, physical maintenance, and social living. Because he may need more than ordinary help in some or all of these areas, the community or significant elements within it would have to be disposed to assist him. And to do this the community would have to accept him as a member. The person who is retarded would need to possess or be shown to possess some characteristics in common with community members. Perhaps, like others in the community, his values include working hard and living peacefully. In fact, most communities will accept a retarded person who manages marginally unless he is labelled retarded, at which point many indeed will reject him. Experience with deinstitutionalization efforts indicates that some communities tend to reject retarded people who are labelled as such. The community sees them as strangers from another world. On the other hand, retarded people who are enabled to grow and develop naturally within their communities are seen as legitimate members, and are not so easily rejected. Between outright rejection and overt acceptance, too, are many ways of rejecting retarded people—subtle, seemingly benevolent ways. Many of the special restrictions placed by governments on the locations and types of residences which retarded people may occupy or the creation of special recreation hours at community facilities are examples.

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[1] Ben-Chieh Liu, *The Quality of Life in the United States.* Kansas City, Missouri: The Midwest Research Institute, 1973.

[2] A similar concern makes computerized matching of clients to service programs a questionable practice if used in isolation from other considerations. This is not just a hypothetical concern, for such systems are underway in several states.

To conclude, two implications stem from our efforts to enable "retarded" people to live well in communities. First, we must continue to inform community leaders about plans for community alternatives and about retarded people themselves.[3] Second, we must be sensitive to the sometimes inconsistent-appearing messages which we deliver. While on the one hand the town fathers hear us saying that retarded people are not much different from the rest of us and that we want a normal environment for them, on the other hand, they hear us planning and demanding "special" efforts and appropriations. Progress will require much understanding and patience of all persons. In time, retarded citizens will become their own best advocates and examples.

CHANGING CONCEPTS OF NEED

Until very recently public policy and professional practices treated retarded people as "deviant" members of society; and not long ago we did not consider their "needs" at all. Rather, we considered the needs of society to be protected from deviant persons. Wolf Wolfensberger has painted an eloquently disturbing and well-researched picture of our historical abuse of retarded people.[4] His work clearly shows that retarded people have always been seen as deviant beings, not really as people, much less as people with needs to which we could and should respond.

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[3] See remarks by Nathan Newman on this subject in Chapter VIII.

The earliest progress differentiated between varieties of deviancy. For centuries paupers, insane people, and retarded people had been grouped into poor farms and asylums. In the mid-1800's researchers and social reformers gave us evidence which showed clear differences among the groups. This led to an early attempt to reform retarded people through education (1840–1880), an attempt which was later seen as a failure. Then a period (1880–1925) which Wolfensberger terms The Age of Indictment, a time when retardation was thought to lead to other social ills and public policy was directed toward the eradication of retardation through isolation, segregation into institutions, and sterilization. Finally, during the Depression and War years (1925–1950) retarded people were simply neglected, placed as they still were in large, economical, congregate institutions, segregated from society. During all of this time, through what Wolfensberger calls the Age of Neglect, the needs of retarded people were not the basis for the way we treated them. It was society's need for protection from deviance.

Unquestionable, the parents' movement (ARCs and NARC) led us into what might be called The Age of Reformation which reached a crest in the 1960's. The national leaders of this movement, the National Association for Retarded Children, promulgated early goals in the document *Blueprint for a Crusade.*[5] The early goals reveal a commitment to dispelling prevailing ideologies about mental retardation and a bold intent to affect the public and professional establishments of the day: emphasis was placed upon research, professional training, and public information. Specific to the issue of needs, NARC aimed to have retarded people recognized, for purposes of *economic needs*, as "permanently and totally disabled"; to have them accepted as "handicapped" for purposes of federal *rehabilitation* programs; and to allow them to receive appropriate

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[4] Wolf Wolfensberger, "The origin and nature of our institutional models," in Kugel, Robert B. and Wolfensberger, Wolf (eds.), *Changing Patterns in Residential Services for the Mentally Retarded*, Washington, D.C.: The President's Committee on Mental Retardation, 1969, pp. 59–171b.

[5] National Association for Retarded Children, *Blueprint for a Crusade*, New York: National Association for Retarded Children, 1954.

diagnosis and evaluation.[6] State and local ARCs were assisted in actions to improve *special education, residential care,* and *community support services.*

In 1962 the federal government first gave concerted attention to these issues as The President's Panel on Mental Retardation delivered its report *National Action to Combat Mental Retardation.*[7] The document reflects some of the best professional opinion of the time about needs of retarded people. The very existence of the report and its far-ranging thought indicate the public and professional progress made since The Age of Neglect. New organizational and administrative concepts were suggested for both federal and state coordination of programs for retarded citizens. This report put forth two new service delivery concepts which underlie present-day approaches to meeting the needs of retarded people. It urged a *continuum of care* throughout the retarded person's life-time and a *fixed point of referral* which would keep in touch with the family and/or the retarded person to ascertain what service needs were met. Substantively, emphasis was placed upon *detection, evaluation and medical care, recreation, religious education, education, vocational rehabilitation, training, employment,* and *residential care.* Significantly, the report viewed residential care primarly as that offered by state institutions, although it recognized other alternatives as desirable. Then, as now, it was expected that generic services would meet many needs. It differed from today's view, however, in that we have come to see the responsibilities of generic agencies in light of the *entitlement* of retarded people to generic services. The 1962 report, on the other hand, relied heavily on enhancing specialized attention by generic agencies through financial incentives, specific law reform, and coordinative mechanisms at the national, state, and local levels. Planning grants to the states were recommended to foster "comprehensive planning in mental retardation" since it was asserted that primary leadership in direct services was a state responsibility. And subsequently, Congress did appropriate funds for state planning, implementation, and initiation of community facilities.

The attention given to retardation by the national and state governments and by voluntary associations between 1950 and 1970 resulted in states developing broad plans in retardation. These plans improved, amplified, or altered the national plan according to lively interest and progress developing within the individual states. Almost every state created improved and more visible coordinating mechanisms for retardation at both the state and substate levels; special services increased throughout the "continuum of care"; and many state and federal laws were written or revised to include special services for retardation.

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[6] Success in achieving these labels for retarded people did help to gain recognition and funds from federal agencies but served also to complicate messages about normalization, as noted on prior pages.

[7] President's Panel on Mental Retardation, *A Proposed Program for National Action to Combat Mental Retardation,* Washington, D.C.: U.S. Government Printing Office, 1962.

Many areas needed further work, however. These areas included the unresolved role of our large institutions and the development of comprehensive non-institutional residential services, specific strategies and policies for prevention, the entitlement of retarded people to education and to humane and unrestrictive treatment, the dilemmas of retarded people living in poverty, and refinements in planning for the needs of retarded individuals at all levels of capability and age. At the federal level, the President's Committee on Mental Retardation has examined most of these areas; in the voluntary sector Associations for Retarded Citizens and others have gone to court and won entitlements; at the state and community level significant efforts are being made to develop high quality, community-oriented services including residential alternatives. Because the way has been so long, though, many of the reformation efforts have been either bandaid or bootstrap operations—redressing the wrongs in existing programs, starting new kinds of services from scratch, creating basic structures at the state and local level to plan and deliver services, increasing the quantity of services, and beginning to insure their quality. *MR 68* documented strides in *early education, day care, vocational training, employment*, and *residential care*. But in many communities of the United States, the vision of the 1962 President's Panel report for a continuum of care and a fixed point of referral for all retarded people remains unrealized.

BEYOND REFORMATION: A NEW RESPONSE TO NEEDS IN SIX DIMENSIONS

What, then, are thought to be the needs of retarded people living in the community today? As suggested at the outset, we should first consider universal human needs. If retarded people are to live as the rest of us, their needs should be considered as needs of the rest of us, according to the *dimension of universal human need.*

The President's Panel in 1962 (and many state plans) considered grouping needs according to physical and mental

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health, shelter-nurture protection, intellectual development, social development, recreation, work, and economic security.[8] The Panel report suggested that these needs would vary primarily with the individual's age indicating a continuum from infancy through adulthood. This presents a second dimension of need, *the dimension of age*.

Since the President's Panel report, our thinking has progressed about the varying needs of individuals limited in capability. Applied to instutional and community programs for all retarded people, the philosophy of normalization challenges us to perceive better ways of meeting the needs of retarded people of all degrees of capability. We must add to our conceptions a third dimension of need, *the dimension of capability*.

The "developmental model," promoted as responding best to our goals of normalization and community life, incorporates three basic assumptions: (1) Life is a process of change, and retarded people change as do the rest of us; (2) Development takes place in a sequential, orderly, and predictable manner; and (3) The rate of development can be influenced.[9] To conform to the developmental model and its assumptions, any consideration of needs must recognize that universal human needs change not only according to age, but also according to capability and development. Thus, *the dimension of change* should remind us that the needs of an individual will alter with his aging and his changing capability as he develops.

Our historical treatment of retarded people has instructed us in the hazards of treating groups of persons as masses of deviants rather than as individual people. One can see the results of mass treatment in the dehumanization which has occurred within our large congregate institutions. Perhaps even more striking and sobering is the evidence of recent research in social psychology which suggests that a normally gentle person will engage in violent acts as long as the situation allows him to depersonalize both the victim and himself.[10] The past should certainly instruct us in the need for *the dimension of individuality*.

When we think of people as masses we forget that each individual is different. Individuals grow, develop, and age differently. Retarded people, like all people, have different abilities and disabilities. And each individual has a unique personality. We can forget, too, that retarded people are citizens with rights. When thinking of people in categories, we often design airtight "systems" of services, which quickly lose their actual sense of purpose and come to exist and self-perpetuate for their own purposes. It is no wonder that many individuals in need are lost or forgotten by the service system.

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[8] *Op. cit.*, p. 76.

[9] National Association for Retarded Children, *Residential Programming for Mentally Retarded Persons, A Developmental Model for Residential Services*, Arlington, Tex.: National Association for Retarded Children, 1972.

[10] Stanley Milgram, *Obedience to Authority, An Experimental View*, New York: Harper and Row, 1974.

Obviously we must consider the needs of groups and create systems. But in designing such systems, we should build in reminders to ourselves of the individuality of the client. We can make services personal, responsive, and accountable. We can start with very basic (universal) elements of human need; and starting from the smallest units of personal need, rather than from agency needs or system needs, we can weave a system which will not by uncontrolled growth evade its basic reason for being—the individual person who needs it. Thus, another dimension for considering the needs of retarded people in the community should be the dimension of individuality, a series of reminders, catalysts, and safeguards which help insure that no one gets placed, lost, or trapped in an inappropriate spot in the system.[11]

The sixth dimension stems from the dimension of individuality for it is a special aspect of that dimension. If a system truly respects an individual, it recognizes individual preferences and tastes as the key to the decisions made within it. *The dimension of choice* should allow a person served by a system of services to be the ultimate decision-maker about the tailoring of services. People choose occupations and vocations, places and ways to live, and friends and companions. Choices make a person unique and underpin his dignity and freedom. Choice, in short, is the fullest exercise of individuality and independence. Without choice, a person is but an object of the choices of others. Even if a system were carefully tailored to meet individual needs, it could neither allow the developmental model to operate to its logical conclusion nor enable the realization of normalization without the dimension of choice. Unless a person has the power and responsibility of choice he is to all others an object. Most especially, he is less human than others. A system of human services above all should respect the choices of those who use it, whether those people are called retarded or not.

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[11] The cynical reader will at this point recognize that even such safeguards cannot insure the development of a *working* system which remembers the individual. The imperatives of political, organizational (bureaucratic), and economic life are such that there needs to be a way of checking *ourselves* as planners, service givers and supporters, a way of insuring that we continue to discover our errors of omission and commission. Comments on this problem are to be found in the final remarks.

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CHANGING ELEMENTS OF SPECIFIC NEED

All persons have the same universal human needs: shelter, health and physical development, and personal and social growth. The dimension of capability will, of course, very clearly define gaps in the dimension of human need.

Shelter. A person living normally will own or rent his own home, although many of us will need financial assistance. One whose capability is somewhat lessened may choose to live in a supervised apartment dwelling, a group home, or a foster home. One even less capable at a given time may live in a nursing home or a general hospital. During his lifetime, he may choose to move from one type of dwelling to another, because of his age or his changing needs. A child whose own family cannot care for him may live with a foster family; he may need to be with a foster family only temporarily, on weekends, during vacations, or during a personal or family crisis.

Health and Physical Development. Most of us can arrange for our own medical care and get what therapies we need on our own; so can many retarded people. Almost all of us need some help in learning to use health services or paying for them. A person whose health problems are more serious will need specialized services and therapies. Some will require constant supervision and intensive therapies. Again, these needs may change with age and growth. They may become more intense, as they do for all of us in old age, or they may become less so if therapies are effective. Similarly, the most capable of us are able to buy and cook our own food. All of us will have to be taught how to do these things, however. If we are retarded, learning may take us more time; perhaps we will need financial assistance to buy our food and maintain our health. Those retarded people with the most limited capability will need to have their food prepared for them and help to eat it. Much progress has been made in teaching the most handicapped to feed themselves; so that we can expect almost everyone's need for help with nutrition to lessen with age and development. Physical disabilities mean that some of us need help getting around our homes and communities. All of us need help when we are very young. A few retarded persons may never be ambulatory, but physical development can be facilitated greatly for most.

Personal and Social Growth. Everyone needs some education to survive in the interpersonal and vocational world. Most retarded people can be educated to meet their needs through public school systems. Some will require a very intensive program of individualized education; and for a few, education will consist primarily of very basic training in life skills. Education should begin very early for those whose capabilities are limited. Most retarded people can be trained for employment or for chosen work activities which are personally rewarding. Many will eventually hold down their own jobs in industry; some will need help finding and fitting into regular employment; some could work better in a sheltered work station within industry; some should be employed in an even more sheltered situation; a few will gain satisfaction from work activity programs and planned recreation. Most will be able, with some initial guidance, to plan and carry out leisure activities with their peers. A good many will need counsel in making decisions about legal issues, money, marriage, and sex; and some will need mental health services.

Only great vigilance will assure that a retarded person's changing needs are met in ways appropriate to his capability and to his age. Moreover, as simple as the foregoing discussion seems, only a complicated planning effort could enact the elements of a service system which will respond to changes in individual needs. A given individual could be charted on the basis of his needs at any given time in his life and stage of development. The individual might have a serious incapacity for health maintenance, but he might be capable in terms of personal and social skills. Thus, a given individual might appear incapable in some respects and very competent in others. Our past mistakes included a tendency to group people in multipurpose institutions or programs according to only one criterion of need; hence, we find severely physically disabled people with significant vocational potential inappropriately grouped with mobile individuals capable only of sheltered activity into an institution serving "profoundly retarded." Similarly, it is not unusual to find aged persons of limited mobility but with potential for activities appropriate to their age placed on back wards of large institutions, being treated as children and even "trained" for youthful activities. Very frequently, adolescent individuals are likewise kept childlike in their personal and social lives. *The dimension of change* demands that we realize that aging and development alter an individual's profile of needs.

Every system of services should be analyzed according to how carefully it facilitates an individual's movement to elements of services appropriate to his changing needs. To what extent a system can fulfill our criteria will depend in part upon the extent to which its elements are financially and geographically accessible to those in need. But it will also depend upon the adequacy of the processes which comprise *the dimension of individuality*. Such functions as appropriate diagnosis and evaluation, information and referral, case management and periodic treatment planning, personal advocacy, protective services and follow-along offer the individual some safeguards against anonymity and abandonment. The *dimension of choice*, aided by these functions, will keep things moving in an appropriate sequence at the appropriate time.

An example of how one area of need (shelter) can be properly considered by the "system" within the five other dimensions is provided in the following hypothetical case and the accompanying chart.

JOHN'S MANY HOMES: HYPOTHETICAL CASE OF AN INDIVIDUAL'S NEED FOR SHELTER

As an infant this retarded individual lived at home and being non-ambulatory had a limited degree of capability. As a child, and through adolescence, John remained with his family. When he reached adulthood he lived first in a group home and later in a supervised apartment. Because of his poor health in middle age, he stayed a few months in a nursing home but later moved back to the apartment.

At point A John seemed to his parents to be very "slow" developing, and the doctor advised the family that their son was "moderately retarded" and should be placed in a state institution. A careful evaluation by the institution's admissions department revealed that the family, with help, could provide good care and training; and supportive services were mobilized to help them and to follow him along through his progress in a special class and vocational training. Although he tried out several kinds of work, he liked the physical work and sense of satisfaction which he got from cleaning and janitorial work. At 22, with help from his school's vocational department, John got a job as a janitor and enjoyed this work for many years.

At point B the family once again considered sending John to an institution because of the parents' advancing age and their fears about his survival alone. Here, a plan for guardianship, a personal advocate, and protective services were arranged; John moved to a group home, retaining his job and forming close friendships at his new home.

At point C he moved into a supervised apartment with three other men from his group home. John's personal advocate wondered if any of the men would like to join a bowling team. Two of them did not want to join in competitive sports but preferred to spend time on hobbies. John had always liked sports and joined the team, which won its league several times.

At point D John entered a general hospital for a brief period, suffering from a serious bout with virus pneumonia. When he was somewhat recovered, the hospital mistakenly recommended that he go to the state institution infirmary to recover fully. His advocate met with the institution staff, and together they were successful in locating a good nursing home near the apartment where his friends were still living. He stayed in the nursing home for two months and was happy to return to his own apartment.

John lived a life not much different from the rest of us. In part, he was lucky to live in a community where resources were available to help him do so. The example shows, however, that vigilance must be built in to keep the resources responsive.

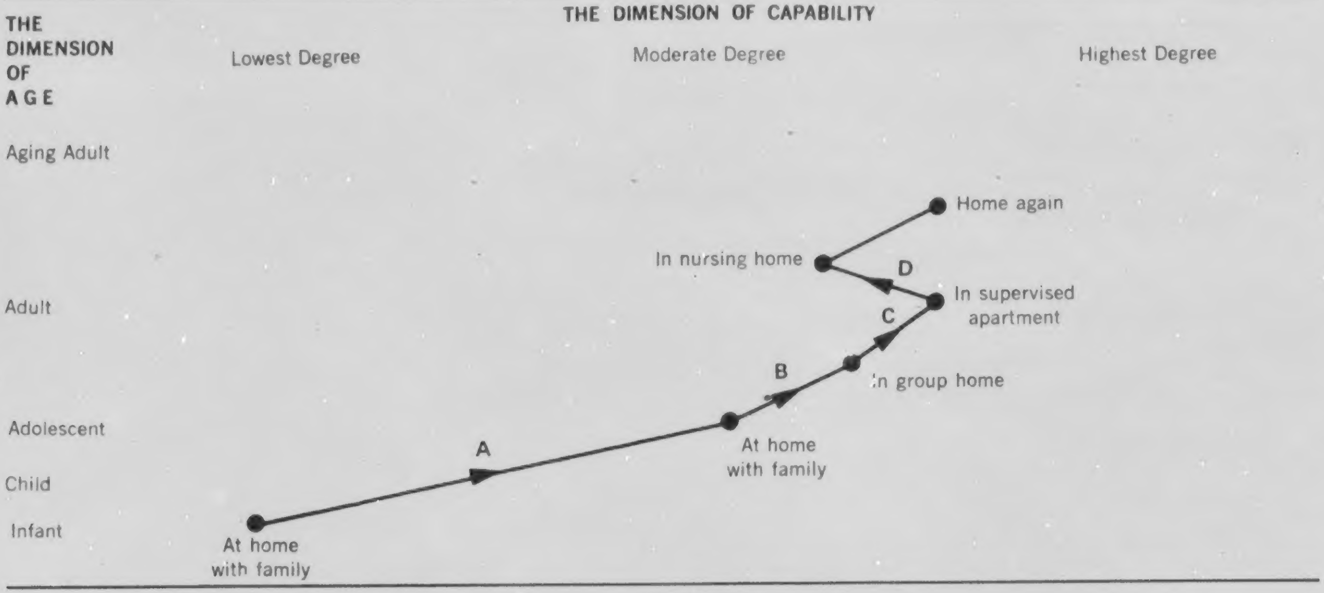
STUMBLING BLOCKS

An ideal is an ideal. Recognizing this, let us now turn to some of the constraining realities: the real imperatives of political, organizational, and economic life. Remembering the past, we should acknowledge that harsh pressures will push us to compromise our ideals to protect society from the confrontations it does not want to make. No society is eager to confront its mistakes and its often less-than-human priorities or to confront people who remind us of our own less-than-beautiful, less-than-brilliant parts. Will we know when we are compromising? To be certain that we know will be difficult, but the first step is to reject our compromise "consumer participation" and to build into policy processes at all levels a voice for consumers themselves and an ear to listen well.

The complexity of organizational and bureaucratic life will make our task increasingly difficult. Complexity reigns in the sources of funds upon which we rely, not only in the variety of sources, but also in the machinery attached to them. Complexity governs the labels we must use, the inter-governmental relations, and the limitations placed upon the uses of funds. Regarding the labeling issue alone, consider that for federal funding we will have to prove that retarded people are variously disadvantaged, crippled, developmentally dis-

JOHN'S MANY HOMES

Hypothetical Case of an Individual's Need for Shelter



Note: Movement of the line indicates *the dimension of change* which occurs in a person's need for shelter as he develops and ages.

The *dimensions of individuality* and *of choice* are highlighted by critical decision points (►), discussed in the case example.

abled, substantially handicapped, former or potential welfare clients, or persons with special needs. One can easily see how we get locked into damaging attitudes. It is easy to see how we confuse consumers. We are probably confused ourselves.

As another reality of bureaucratic life, "human services reorganization" is sweeping the country with massive reorganizations of state government accomplished in nearly half of the states. While retarded people suffered from being physically grouped with "paupers and insane" in the 1800s, they have suffered from being bureaucratically grouped under "mental health" in more recent years.[12] Now they are grouped in bureaucracies with even broader concerns. The rationale of efficiency and better human service delivery, while admirable in its own right, does not apply well to the particular individual needs of retarded people. We will have to be alert to design "systems" within the human services structure that have an *identifiable* subsystem, such as the one described earlier in these pages, which responds to the human needs of retarded persons in particular.

Perhaps one of our greatest stumbling blocks is economic. The necessity to economize tempts us constantly to lose sight of needs; yet resources—human, financial, and capital—are limited. Because of this we must economize, and economizing means making choices and foregoing opportunities, drawing boundaries and making exclusions. The nature of major financial resources further inhibits choices and constricts boundaries. Most of these resources are not designed especially for retarded people. At best they would serve retarded people along with other "categories" as mentioned above. Thus, as we choose a particular funding source, we are often constrained to exclude some individuals from the service segments which that source favors. We must also make choices which limit the geographical areas to be served. We must find particular locations for service facilities. We may have to focus our services on a particular segment of the population. Every choice implies foregoing other choices. Thus, any choice—be it geographical, locational, or population-based—means that some people will lack a particular service. And some retarded persons' pressing needs will not be met, often not even considered.

Economizing also means trying to achieve the most "output" for one's investments. "Cost effectiveness," "economies of scale," and "marginal utilities"—terms and methods which have begun to flood the human services field as it strives to

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[12] Gunnar Dybwad, "Psychiatry's Role in Mental Retardation", in Bernstein: *Diminished People*, Boston: Little, Brown and Company, Inc. 1970, p. 144ff.

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appeal to the purse—simply ask, "Can we afford to invest in this business?" The massiveness of institutions for retarded people was at least in part due to "economies of scale." The preference of rehabilitation and other programs for concentrating on the person with high potential for "output" reveal a "cost effectiveness" mentality. And clearly, in political terms at least, the "marginal utility" of investing in retarded children and encouraging investment in them was for a long time considered greater than investment in retarded adults.

Philosophically, we have begun to overcome these narrowings of concern. We will be continuously tempted, however, indeed we will be constrained, to document our "cost effectiveness." And this will try the mettle of our new philosophies. If we do not persist, our systems will not meet many retarded people's needs or, again, even consider them. Especially excluded will be those who are less capable.[13]

Few would disagree that we should account for the investments made in our clients. Certainly, people are entitled to know what happens to their money. On the other hand, a strictly economic justification can probably never be achieved in the human welfare field. It is neither possible nor desirable to quantify all human needs and all of the benefits of programs designed to meet them. The trend toward "individual treatment planning" for consumers of human services is healthy, for it recognizes this reality and places the accountability issue more appropriately between the consumer and the agent of service. If indeed such individual treatment plans can generally demonstrate their worth for the consumer, the challenge to us will be to convince the funding agents that this in itself is the fullest accounting necessary.

Few would disagree either that we will always have to make "economizing" choices in applying our resources. Hence, boundaries on staff, facilities, target areas, clientele, and organizational identities will remain.

SYSTEMIC ADVOCACY

Overcoming these problems will require a series of strategies which might be called "systemic advocacy," for these strategies are directed toward advocating the needs of the individual at the level of political, bureaucratic, and economic systems. Systemic advocacy will address gaps in the "service system," weeding out the murky undergrowth of complexity and thinning the massive overgrowth of bureaucracy.

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[13] See Ronald W. Conley, *The Economics of Mental Retardation*. Baltimore, Maryland: John Hopkins University Press, 1973.

As Robert Perske points out in his chapter, "New Directions for Volunteers," the voluntary movement of parents and friends of retarded citizens can uniquely monitor a system of services. Associations and the ad hoc groups which he describes can watch the elements of the service system, checking within system elements on quality and quantity of services. They can also patrol the boundaries of those elements and locate needs between them. Then they can organize to find ways of meeting those needs. But this unique ability of theirs will itself be constrained by their tendency to perform the service-providing role.[14] As their own service delivering increases, they too must economize and narrow their vision; they will set allegiances to boundaries in relation to the service element and lose perspective on the voids between the boundaries, becoming beholden to funding agents and others whom they should be monitoring and whose boundaries they ought to patrol. The malfunction of such an arrangement is analogous to the clearly documented political theory and research which states that a "crisis in public authority" results when the organized regulated entities become entwined with the regulatory authority.[15]

Another kind of systemic advocacy exists within the public sector itself. Although still youthful and some claim problematic in its conception and development, the Developmental Disabilities Services and Facilities Construction Act of 1970 was a landmark piece of federal legislation in its intent: that a state level planning and advisory group review and evaluate the quality and scope of existing services for developmentally disabled people and see that "gaps" are filled. The Commonwealth of Massachusetts has given the program the leadership of a staff (Bureau of Developmental Disabilities, Executive Office of Administration and Finance) and a planning and advisory council (Mass. Developmental Disabilities Council) which has had extensive experience in planning and advocating for retarded persons. Here, an exemplary approach to fulfilling and even going beyond the federal legislative intent has resulted in a public social planning method which directly addresses the problems of boundaries and the gaps between them. A major emphasis is placed upon the reform of discriminatory public policies and not upon the design of "special" (segregated) efforts.[16] Working closely with other public and private agencies, the Council and its staff seek to fill gaps by reforming both federal and state legislative and administrative law, by "seeding" and supplementing gap-filling efforts of other organizations, and by stimulating the policy analysis and reform efforts of others. As noted in the case of the voluntary movement role in monitoring and patrolling boundaries, a key to the objectivity and comprehensiveness of this form of "systemic advocacy" is the relative freedom of both the Council and its administering agency from the direct service delivery functions.

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[14] Wolf Wolfensberger, *The Third Stage in the Evolution of Voluntary Associations for the Mentally Retarded*, Toronto: National Institute on Mental Retardation, 1973.

[15] Theodore Lowi, *The End of Liberalism*, New York: W.W. Norton & Company, Inc., 1969, pp. 86–90.

The final, perhaps ultimate, systemic advocacy method uses judicial recourse on behalf of the rights movement. The movement toward the guarantee of rights to education and treatment and the right to the least restrictive alternative, of course, results from the two previously cited forms of advocacy. But judicial recourse and its results deserve mention as a separate form. The rulings which have already been made have provided great force to "deinstitutionalization" efforts and have served as important tools in the change process through executive and legislative branch channels. The rulings and the ensuing legislative and executive policies directly relate to this chapter. They are intended to cut through the political, bureaucratic, and economic constraints to guarantee *individual* rights. And some would argue that only such fundamental reforms can guarantee that an organized society will respond to the human needs of its members rather than its represented interests.[17]

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[16] Some documentation of the approach can be found in Bureau publication, *A Guide to Service and Exclusion Policies in Public Programs of the Commonwealth for Retarded and Multi Disabled Persons*, 1970, and in the Council's State Plan for 1973.

[17] Theodore Lowi, *The Politics of Disorder*, New York: Basic Books, Inc., 1971, p. 177ff.

CHAPTER II

LISTEN! LET US SPEAK

by Robert Audette

"What they should have done is ask us how we feel about it, instead of telling us."

This chapter presents quotations from some persons designated as mentally retarded. Selected graduate students and I talked with people who live in institutions and others who were formerly institutionalized, but now reside in community homes. We met adults who have lived all of their lives at home. We chatted with children in church basements and schools and discussed a variety of current issues with young married adults as well as old people in nursing homes.

First, we had to learn about ourselves. We discovered that the long absence of communication between ourselves and those we intend to serve was caused *not* by their lack of ability. This silence clearly reflects our inability to communicate with others. At first, we barked our questions—as though they couldn't hear; we articulated slowly—as though they were babies; we talked at them—as though they weren't people. How remarkable our own lack of judgment in asking a young man how "people like him" felt about the right to marry.

As decision makers we have been prepared to be responsible, and we have chosen the direction for our own lives. As administrators, parents, and professionals, we have come to accept the same burdens of decision for "their" lives. Our preparation in school, in church, in court, and in other forums has classified the difference between "us" and "them." "They" are dependent, childlike, and limited; thus, "they" are intrinsically unable to choose or to participate.

We theorize; we hypothesize; we experiment and implement; we analyze.

They are evaluated; they are studied; they are categorized, placed and reassessed.

To serve and do "what is best" for them, we have overlooked the obvious; we have ignored the human bond between us. Even though we believe differences are normal, we have steadfastly suggested that adaptive behavior implies doing something "our" way. With these persons, our early nervous demeanor said much about our naivete. We did learn from them, however.

This chapter provides a forum for the one hundred and eleven persons who shared their time with us. It does not generalize beyond the immediate impact of the quotations. Like the rest of society, persons classified as mentally retarded espouse wide-ranging personal, spiritual, and political attitudes. This was our first lesson. As in any group, regardless of environment, we discovered ideas ranging from overly simplified notions of our complex society to realistic evaluations of both hopeful and hopeless situations.

Ambition and hope are entangled with inaccurate notions of employment and basic tenets of the Protestant Ethic in the remarks of a young man we met in an occupational training program. He spoke enthusiastically about work:

> *"I'm going to find a job. You can get one by looking in the directory. When I work I'm going to make $26,000 a year 'cause that's what you get when you work hard."*

His words sharply contrast with an appraisal of some staff members by an institutionalized young woman:

> *"Them people that work here at   are nurses and you can't tell me they been to school. They don't know as much about people as most of the residents."*

A 21-year-old woman discharged from the institution at 17 now living with her boyfriend in a small apartment near the institution reflected on marriage:

> *"If we want to get married and they (the institution staff) say we can't, I'm going to be real mad. I'd just tell them that I want to get married 'cause I want to have a kid so he can go to school and get smart."*

Although successfully employed for two years as an aide in a nursery school program and legally free of the institution's control, this young woman continued to feel its imprint over her sense of choice. This feeling of dominance by others is hardly peculiar to persons with institutional backgrounds. A young man of 17 in a high school special education program wanted to take driver's education, but didn't sign up because his teacher persuaded him against it.

> *"My teacher says she will take me out soon and then I will park it nice. Then the policeman will give me a license."*

Parental and professional dominance by dishonesty was a discovery confirmed many times as we listened. A 9-year-old girl in a public school class reported that her mother told her

> *" . . . the Girl Scout Dance isn't safe because I could have a baby who would be sick like me—but when I'm 15 I can have an operation and then I can dance."*

Some may rationalize deceit by those who "know best" as necessary to run an efficient program within an inefficient system, but such lies result only in confusion and dismay for the recipients. The constraints imposed by the protective attitudes of those in charge puzzle a middle-aged woman who wants privacy:

> *"If I had a chance I would like to try a halfway house—with my own age. I would have my own room. It's dangerous, that's the hard part of it. In my own room, if I black out ever, which I don't black out—that's one thing I never could understand. I don't black out at all."*

Many ideas expressed arose from inept explanations, as evidenced by a 12-year-old boy in an elementary school class.

> *"I'm going to be smarter later. Some kids call me dumb and retarded. Daddy says I am now—retarded I mean—but that's because I don't eat good and behave enough. When I'm good, I'll be cured."*

Further, our own foolish questions have bred foolish responses. When we asked several adolescent girls at a summer camp what they would do if they owned the camp, their responses demonstrated both serious and silly ideas:

> *"I'd sleep late."*
> *"I'd get a TV and let everybody go and swim and I'd watch."*
> *"Bring boys here."*
> *"Fire .... (A counselor)."*
> *"Give everyone $100 and go shopping."*

For some, these responses may confirm a sense of security that non-adaptive behavior is inherent among those classified as retarded. These so-called 'unrealistic' attitudes may, however, merely reflect narrow experience, deceit by those in control, and non-adaptive behavior by those of us working as professional planners and service providers.

Despite the handicap of being dominated by limited and unrelenting control agents, some persons we met demonstrated quick humor, which caught us by surprise.

A nervous interviewer trying to broach the subject of sex and sterilization to a 17-year-old young man finally resorted to a forthright question:

> *"Do you know what sterilization means?"*

The young man laughed and said,

> *"I can get my dictionary if you need it."*

An 18-year-old outward bound young man described the professional-client relationship in a manner contrasting with text book dogma:

> *"He can't help me. He needs help himself. He needs his white coat on or he gets real fidgety. And he blinks so much and keeps crossing his legs. He's a nervous wreck. I got a problem and I need to talk to a 'man' about it. When I see him I feel worse 'cause all his moving around and stuff just makes me nervous. I'd rather talk with* .... *(A custodian at the institution). He understands about chicks. He ain't no shrink but he helps me think. That other guy is going to fall apart if they ever hide his white jacket."*

A 14-year-old boy in a Junior High special class expressed a similar attitude with a different target:

> *"I like most of my teachers except for the mentally retarded one. I hate her class 'cause she ain't a regular teacher. She doesn't really teach—I don't think she expects us to learn nothing. In high school it'll be better 'cause there ain't any retarded teacher there."*

Our interviews often turned up profound ideas and sensitive perceptions of our systems:

> *"Being in the institution was bad. I got tied up and locked up. I didn't have any clothes of my own and no privacy. We got beat at times but that wasn't the worst. The real pain came from always being a group. I was never a person. I was part of a group to eat, sleep and everything. As a kid I couldn't figure out who I was. I was part of a group. It was sad."*

Despite these retarded persons' limited experience and the narrow worlds built for them, many of our conversations revealed a breadth of understanding. Physically constrained by his walker and further limited to the walls of his ward, a young man discussed marriage in terms of advantages and disadvantages:

> *"I do not want to, but I don't want to make it miserable for the girl, either . . . There are a lot of things I can't do. I can't drive—she'd have to drive me. And there's a lot of other things I can't do too, like shoes and things like that . . . And lifting the wheelchair—that's heavy."*

The oppression of the institution cannot dull an astute sensitivity to social dynamics as shown by a young man responding to a question about friends:

> *"Well, I know that when I was at , the ones that tend to be my friends were trying to set me up like. Once they were my friends and they would give me things or something and then they sort of made a fool out of you."*

Even though breadth of understanding includes an awareness of the obvious, the stigmas of isolation and of labels have escaped planners and administrators for a long time.

> *"They didn't call me retarded outside—just here at . Outside no one knew. You act like they act—no one knows you're retarded. The only way they'll know you're retarded is if they're told by someone else."*

The disrespect felt at being referred to as children was another insensitivity recurrent through our visits.

> *"They call us patients 'boys.' They should at least call the older boys 'men.'"*

Strength of resolve and resistance to being demeaned by those "in charge" shine through the statement of a multiply handicapped young man:

> *"I've never answered to that title—patient. I have answered to the title 'resident.' But ever since I've lived here and even today I wouldn't dream of answering to the title of 'patient.' I like my own name."*

On the other hand, a young man newly arrived in a community group home expressed the joy of being accepted without ceremony.

> *"When I came back from work—I was riding my bike home late—these two ladies. One of them says, 'Good evening sir.' I said, 'Good evening ma'am.' It made me feel good and she said, 'Nice night.' I said, 'Yes it is.'"*

Although we witnessed beauty in unsightly settings, the ugliness bothered us. But it has failed to stamp out the highest forms of feeling. Solicitude for others was a precious lesson for all of us. The following physically handicapped man could move slowly in his wheelchair; the woman could move in a walker, but the physical strength for much movement was not available to her. He helped her:

> *"She can only move her walker a little bit, and she'll ask me to walk her and we do it with her holding on to the back of my wheelchair. Then she can walk, I'd say, almost the length of this hall and back again. We only do it when she wants to because one of her legs is really untrustable."*

The evidence of informal organizations and systems for supporting each other was relatively consistent in institutional settings. The character and quality of these underground systems is typical for repressed peoples. A teenager warned us:

> *"Don't tell them a resident told you. The resident'll get in trouble. We're not supposed to be so smart; we're not supposed to know everything. They think we haven't got enough sense to know. You'd think after they got to know us—but I've been living here for 4 years—they don't know me yet."*

The informal systems keep the membership informed:

> *"We've got ways of finding out, you know. We got good connections, let's just put it like that. But that's the way they really should do it. They should ask us—you know, the residents—what they think about things and everything, instead of going around asking the wrong kind of people. They ask the employees. But they really should get us in one of those conferences. We'll tell them some things that'll burn their ears off."*

Listen! Our brothers and sisters can speak for themselves.

> *I'd tell them just how this place is. I'd tell them they just don't do us right. You know, they treat us all right and everything, but they should ask us our opinions about some of the rules they put out. Like not going outside by ourselves. 'Cause on a pretty day, you don't want to stay stuck up in no hospital."*

Listen! Not just for a moment! Unless we constantly listen we can't promote choice and growth in independence.

> *"Listen, this is not a jailhouse. We want this place to feel like a home, not like a prison. The employees would have to improve more. To make them improve; to make them realize that this is not a rat-hole of a jungle. A wild jungle."*

> *"He goes to the wrong kind of people. When Dr. ______ first came here he used to have meetings with us and he'd get our opinions about everything. But since then, none of that's been happening. And myself, I don't think it's fair for us, 'cause we have to find out the hard way."*

Listen! Not for the sake of democratic process, but because they are speaking. We have been tinkering with people's lives.

After forty years in an institution what if a person wants to stay? What if the ward, bad as it is, represents all the home and friendship known to an old man?

> *"I say it's this way. Someone who's going where they don't want to go, shouldn't have to. They should go in and talk about it first."*

What if the attitude and rules of community residence are as repressive as those of the institution which a person left?

> *"Mrs. ______ unlocked the door and came in. I said, 'Mrs. ______, I'm going to bed.' She said, 'You ain't going to bed. I'm going to see your quarters.' She will—if she sees you're in bed she'll unlock the door and come in. You try your best to get out of that place. They don't even give you any help. The only thing they give you is a bunch of lies."*

What if the staff's insensitivity removes the last vestige of privacy by destroying the value of sleep?

> *"I think one thing they ought to change is about these nurses—talking so loud, especially at night-time when you're trying to sleep. And they play the radio where you can hear it all the way down to your bed at the other end. And they get to talking real loud at night-time and they don't really care."*

What if the staff's needs and interests supersede the wishes and needs of those the staff is employed to serve?

> *"Last night I was watching TV and then he come up here—oh, he made me mad. Every time they want the TV station turned they just walk up in front of everybody and go turn it, and don't make no beans about what you're watching. That don't mean a thing to them."*

What if administrative prerogatives to protect the "patient" trample basic civil rights?

> *"Even when we get letters from other people they read them. And we're not supposed to give letters to the vol-*

> *unteers to take them out. We're supposed to go all the way through Ms. .... It's not fair. She told me one time they were going to see about not letting her open letters any more. They haven't done anything since then."*

What if the staff determines that the threat of subversive activities requires examination of all incoming possessions?

> *"Most of the time she opens packages. Course she didn't open my last package 'cause it was about time for her to go home. But I believe if it hadn't been, she'd have opened it."*

What if a program stifles ideas of choice and judgment?

> *"See, they pick the stuff out for you, then they pay for it. They don't even let you pay for your own stuff. They make you buy what they want you to wear."*

What if the staff actually prepares people for subservience by denying access to skills necessary for success in the community?

> *"They don't teach you how to handle money. They keep it all in the office and keep it for you. That ain't no good. What are you learning to do? You ain't learning nothing."*

What if the product of years of dependency training results in acceptance of a dependent role?

> *"I'd just as soon have restriction, 'cause restriction don't bother me. 'Cause if I want something all I have to do is send a kid up there to get it for me. If I want a pack of cigarettes—just send someone out. I get to sleep, don't worry about work. It don't hurt me."*

Listen! It is not too late for us to learn; we have not taught the concept of choice.

Most of the people we met want to live in the community, but not all wish to move. We heard people say that they would like to participate in a real way in selecting a home and a life style.

Listen!

> *"I've been here 4 years and 2 months. They don't talk to me. They don't know I'm around. They don't know me at all."*

Listen!

> *"I've been living here 5 years, going on 6. Be 6 years the 14th of this month. You just haven't lived here, so you don't really know."*

CHAPTER III

WHOM DO WE CALL MENTALLY RETARDED?

by Gunnar Dybwad

This book is about people, people referred to as being mentally retarded. Through the centuries much has been said about them, about their being dangerous, evil, possessed, or, to the contrary, special gifts from Heaven, "holy innocents."

Many of these beliefs live on. One can encounter them even today almost anywhere in the United States as plans are discussed for community residences for mentally retarded persons.

Yet mentally retarded individuals have lived in our communities since time immemorial. Over the past decades many of them have gone to public schools, not by the thousands, but by the millions; in increasing numbers they are employed in business, industry and government. They travel by bus and subway, go to ball games and movies, and some even vote at the polls.

This is not an idealized picture, but it is just not a complete picture. Many mentally retarded individuals, severely and multiply-handicapped, whose functions and activities are extremely curtailed, spend their days in idleness in institutions.

First, then, we must learn that being called mentally retarded has very little meaning. Mental retardation is not a very descriptive or revealing term; it cannot convey an adequate picture. There is too wide a difference between the retarded young adult who leaves his community residence in the morning, joining the subway crowd on his way to work, and another retarded person who spends his day in the ward of one of our large state institutions, idly shuffling about.

In the face of such a wide range within the group considered to be mentally retarded, efforts have been made through the years to establish a terminology for the different degrees of this handicap. In the early part of this century people differentiated between idiots, imbeciles, and morons, depending on the extent of their mental retardation, with the moron being the least severely involved.

With the introduction of the intelligence test, developed by Binet in France, and brought to this country by Goddard, it became an accepted practice to relate these three terms to specific I.Q. scores *—idiot for those scoring below 25, imbecile 25 to 50, and moron 50-70/75. Later on the terms "severe," "moderate," and "mild" replaced those terms, but conceptually no change occurred. It was firmly believed that not only could the degree of mental retardation be definitively tied to fairly restricted scores on intelligence tests but, more importantly yet, that this was an unchanging static designation. Not only "once retarded, always retarded," but also "once moderately retarded, always moderately retarded." The I.Q., it was commonly accepted, was fixed. Moreover, it was believed that the I.Q. ratings and the three part classification—mild, moderate, severe—could be tied very closely to a level of functioning, circumscribing quite narrowly what such a person could not do in terms of daily living and learning. Whether a Person received an I.Q. of 71 or 68, of 52 or 49, could have the most far-reaching consequences for his lifetime, because that difference was the key to decisions about the service which he would receive or from which he "had to be" excluded, and more likely it was the latter. As one educator* has succinctly expressed it, "While the difference between *becoming* or not becoming mentally subnormal may often be slight, the difference between *being* and not being mentally subnormal may be considerable."

Overall, the steady progress of urbanization, industrialization, and specialization and the sharply increasing life tempo and competitiveness decreased the tolerance for retarded individuals, and less and less was there a place for them in the community, socially or even physically.

In the late nineteen forties and early fifties into this situation broke the movement or, more appropriately, the rebellion of parents of mentally retarded children. Throughout the United States and Canada, in England, France and Scandinavian countries, in Australia and New Zealand these parents stood up and demanded that their children not be denied the privilege of schooling, vocational training, and meaningful occupations.

Although some educators quickly supported the parents' demands (and, indeed, a few school systems had heretofore for many years successfully conducted classes, not just for mildly but also for moderately retarded children), overall the field of education reacted negatively. The education profession remembered that high hopes for the educability of mentally retarded individuals during the second half of the nineteenth century had led to severe disillusionment, and to this was added the negative impetus of the "eugenic scare" during the first two decades of the twentieth century, which looked upon the mentally retarded person as a menace to the well-being of society.

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* The concept of the Intelligence Quotient as related to Binet's mental age was developed by W. Stern.

* Albert T. Murphy as quoted in Burton Blatt's *Christmas in Purgatory*. Boston, Mass.: Allyn and Bacon, 1966.

When parents pushed on and in many communities actually organized classes for the moderately retarded (that is, children with an I.Q. between 50 and 25), educators responded with a terminological sleight-of-hand, the effect of which is still haunting community planning. They introduced a supposed philosophical and methodological difference between educability and trainability. Mildly retarded children, those with an I.Q. above 50, were termed educable; the moderately retarded were considered ineducable but trainable. Also, many prominent leaders in special education believed that this "training" was not a responsibility of the public schools but a "welfare" job. Those below the "trainable" level, the educators chose to call "custodial" cases, suggesting that nothing more than safekeeping could meet their needs.

In the ensuing years this viewpoint failed to prevail as, under pressure from parents, legislation was enacted in more and more states making the education of the so-called trainable child a mandated task of the public schools. However, the terminology remained, and with it the static viewpoint toward mental retardation on which it was founded.

This terminological effort of the special educators created serious and pervasive damage in two ways. Without sufficient evidence a sharp dichotomy was created between the learning process and learning capacity along the hairline of an I.Q. of 50. Furthermore, what might have been justifiable as a designation of two different teaching methods was perverted into a label affixed to individual children with the clear implication that a child, once designated trainable, could hardly be expected to move up to the more advanced type of instruction appropriate for educability. Unfortunately, the labeling did not stop here, but post-school community services such as vocational training centers and workshops adopted it as well, thereby carrying over the label of ineducability into adulthood, through the tasks to be performed by mentally retarded adults in a work situation might differ sharply from those in a classroom situation. Fortunately, the rather negative exclusion-oriented attitude of professional educators changed radically, most noticably following the mid-sixties. This shift in attitude culminated in a strong policy statement passed at the 1971 annual conference of the

Council of Exceptional Children, the national organization of teachers, supervisors, and administrators in special education. This significant six-page document entitled "Basic Commitments and Responsibilities to Exceptional Children" explicitly states that education is the right of all children and that educational opportunities should not be denied to any child regardless of his potential for contributing to society.

While the foregoing developments took place in the field of special education, other changes occurred in the general terminology and classification of mental retardation. The American Association on Mental Deficiency, in 1959, issued a revision of its *Manual on Terminology and Classification* which contained three important changes. In contrast to other classification schemes, such as that in use by psychiatrists which tended to lump together all retarded persons with an I.Q. below 50 as essentially incapable of development and in need only of protective care, the 1959 AAMD classification, on the basis of demonstrated differential capacity and performance, suggested a three-level division of those with I.Q. below 50 into moderately, severely, and profoundly retarded. Furthermore, in the definition of mental retardation, this revision added to the factor, "subaverage intellectual functioning," a second factor relating to social adaptation, "impairment in adaptive behavior." Finally, the Manual brought into the realm of mental retardation a grouping formerly known as having borderline intelligence. It did so by decreeing that (subject to the criterion of impairment in adaptive behavior) a differing mathematical cut-off point was to delineate mental retardation (to wit: one standard deviation below the norm) and that this psychometric grouping of people would henceforth be designated as borderline mentally retarded.

The first change, the creation of the new category of profound mental retardation, proved to be very useful from a practical viewpoint; it focused attention on this long neglected group of individuals who populated the back wards of the state institutions. Studies and demonstration projects soon revealed that this group could respond far better to simple training efforts than had been assumed, and was even more responsive to environmental change when the back wards were changed into something a little bit more resembling human habitation. Furthermore, in many cases the severe physical impairments with which these individuals were afflicted appeared to be a major factor in their extremely low level of performance, and upon remediation (for example, through orthopedic surgery, physical therapy, and so forth) a distinct improvement in their level of functioning occurred. This suggested that the group might be better referred to as profundly handicapped rather than as profoundly mentally retarded.

There was a great deal of positive response from the field to the second recommended change, the addition of the concept of adaptive behavior. Unfortunately, however, tests for the application of this new criterion were still in the early stages of development and fifteen years later are still not part of most psychological evaluations. In other words, in spite of increasing doubt about the sufficiency of the intelligence test in the determination of mental retardation, it has remained from a practical viewpoint the sole determinant.

Yet more significant, from this chapter's focus, was the response to the third recommendation, the establishment of the new "borderline" category within mental retardation, which vastly increased the supposed number of retarded individuals in the United States. What happened was that fourteen years later, in 1973, the American Association on Mental Deficiency published yet another revision of its Manual and with one turn of the printing press removed from millions of American citizens the burden imposed on them in 1959 of being presumed to be mentally retarded, albeit on the borderline level only. AAMD simply lowered the upper cut-off point for mental retardation not one but two standard deviations (e.g. an I.Q. of 68 on the Stanford Binet test), subject of course to the second criterion, impairment of adaptive behavior.

Here, then, this chapter's question "Whom do we call mentally retarded?" comes into sharp focus and brings forth a rather disturbing answer. We call mentally retarded those whom "we" choose to call so. And, who is the "we"? In this case of classification and terminology it was a professional organization working in the field of mental retardation which entrusted this task to a committee and did not even see a need to have the sweeping revisions ratified by a vote of the membership. Thus in an unmistakable way the American Association on Mental Deficiency has clearly supported the thesis put forth by one outstanding social scientist active in the field of mental retardation, Dr. Jane Mercer of the University of California. Dr. Mercer maintains that mental retardation is not so much a clinical designation based on compelling evidence as it is a social status conferred on individuals by whatever societal group has been given, or has taken upon itself, the right to so label people.

The President's Committee on Mental Retardation has illustrated this view with its widely distributed booklet *The Six-Hour Retarded Child*, the child who five days a week, from nine to three, *has the status* in school of being retarded but who is not so considered while moving about in the community.

But this is not the only example. Those concerned with statistical studies in mental retardation have long been aware of an intriguing phenomenon—the number of "known" mentally retarded persons in any community drops sharply for the older out-of-school group. Once a young adult has left school and on his own has secured employment in the community, he may "lose" his status as a retarded individual and may be accepted at his place of employment, as well as in the community at large, as just another young citizen.

In other words, as we set out to develop new plans for community services for mentally retarded persons, we need to remember that tens of thousands of substantially mentally retarded children, adolescents, and adults are now and have been for many years living, walking, and working in our cities and towns, have attended public schools, have gone to camp, have used streetcars and subways, have voted and held a vast variety of jobs. While many of them, maybe the majority, were and are known to some as retarded individuals, many are not so recognized in day-to-day living. Yet other individuals are so handicapped or conduct themselves in such a fashion as to be seen as manifestly retarded. We must understand that the *status of being retarded is open to change*, and the record will show that our predictive capability is limited.

Less dramatic perhaps, but to the individual involved of great significance, is a further and related phenomenon: The level or degree of mental retardation originally bestowed upon an individual by a clinic, school, or institution may also change. The individual who once sat in an institutional back ward, half naked, aimlessly rocking back and forth, and "obviously" profoundly retarded may later be seen in a sheltered workshop in the community, operating some simple mechanical equipment, properly dressed and maintaining human contacts—verbal or non-verbal—with others around him.

Of course, at least presently, certain groups of children or adults need more or less extensive nursing care for an unspecifiable time. But their condition clearly does not require confinement in a large state institution. They have a right and the capacity to be in an appropriate community facility, with an open door leading to a less restrictive, less restraining environment. Only time will tell who will use that open door.

And that brings us to the question: How many retarded persons are there in our community? This invokes a counter question: How retarded is retarded? Shall we be guided by the

1959 or the 1973 definition of the American Association on Mental Deficiency? The by now traditional statistical view was predicated on a three percent figure. But no one has yet been able to find the three percent mentally retarded persons in any large unselected population group. Two scholars who have given this question much study, Professors Burton Blatt and George Tarjan, put the incidence of mental retardation in the general population at no more than one percent, and quite likely less.

Furthermore, even if one could say with certainty that a given community has today one hundred individuals waiting for a place in a community group home or other facility, it would be hard, indeed impossible, to predict for how long each one of them would need to stay there or how soon they could move to "regular" unsupervised living quarters. Broad statistical generalizations will be of very limited use in this context.

Our knowledge of the developmental potential of individuals labeled retarded is as yet insufficient for long range estimates. A parallel will make this clear: Had we rushed in, nationwide, in the nineteen fifties and sixties to build special schoolhouses for children considered to be only "trainable," we would now have white elephants on our hands from coast to coast.

The question "Whom do we call retarded?" is best responded to by a counter-question: Why *call* anyone retarded? Webster's dictionary says "to call" means among other things "to utter in a loud or distinct voice," "to read over (a list of names) loudly," "to give a name to" and "to regard or characterize as to a certain kind."

Perhaps the significance of the question and counter-question will become more apparent if we take our cue from the last definition and explore what "certain kind" we mean when we use the term mental retardation.

At least to some extent the answer to this question will surely come from young and not so young mentally retarded adults themselves, whose emergency from the once nebulous mass characterized as mentally retarded is providing us with an exciting and challenging drama. One can already clearly discern the first indications that some of these people, once knowns as "docile retardates," are no longer willing to sit in the back of the bus. Education is a powerful tool; the withholding of education and of knowledge has been practiced through the ages by benevolent as well as oppressive rulers in Church and State. Education and a new tool, "advocacy," are now helping the retarded citizen to assert himself and to protest a label that he sees as a libel.

PART 2

RIGHTS AND INDEPENDENCE

CHAPTER IV

THE RETARDED CITIZEN AND THE LAW

by Donald Freedman

Between October 1971 and July 1973 at least forty-one court actions were initiated in the federal and state courts of the United States on behalf of persons classified as mentally retarded. None known to this writer has been filed before 1971. Nine of these actions were based on the "rights to treatment," seventeen on the "right to education," five on the "right to live in the community," four on the "right to just compensation" and so forth.[1] These cases and the rights they enumerate have come so rapidly onto the socio-legal scene that full implications and the origins of their terms may be buried before they are fully discovered.

To determine where we have been, where we are, and where we might be going in this dynamic social action area, this chapter will attempt to step back from the current cases and evaluate relationships between changes in legal rights and changes in mental retardation policy.

The following broad trends appear again and again in the law and will be highlighted in this chapter: a trend from the broad categorization of mentally retarded persons to a focus on individual differences; a trend from a perception of mentally retarded persons as being incapable of growth beyond narrow limits to a focus on their developmental potential and particular strengths; a trend from a perception of mentally retarded persons as significantly different from "normal persons" to a focus on the degree to which we all share the same aspirations, feelings, and fears; and, perhaps most importantly, a trend from enforced dependency toward self-determination and responsibility.

Rather than attempt an unrealistically comprehensive survey of all the laws affecting mentally retarded persons and of the way these persons are perceived by society as exemplified in those laws, this chapter will focus on several particular areas of legal rights. Examples will come from Constitutional and from state law. From these examples, the chapter will draw inferences about the future of the law in these and other substantive areas and about the future of society's perceptions of persons it calls mentally retarded.

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[1] Paul Friedman, "*Mental Retardation and the Law: A Report on Status of Current Court Cases.*" U.S.D.H.E.W., Office of Mental Retardation Coordination, April and July 1973.

The first major section of the chapter will attempt to discern the meanings of the major term, "rights." The ascription of rights to a class or persons has social as well as legal significance, the one mutually reinforcing the other.

The second section will discuss the most critical unresolved issues which must underlie any discussion of the rights of persons classified as mentally retarded: What is the meaning of "rights" for an individual not only handicapped by his being classified as mentally retarded, but often so intellectually or behaviorally impaired that he cannot advocate on his own behalf? What implications does this dilemma bear for advocacy systems of all kinds: citizen advocacy, legal advocacy, consumer group movements, and so forth?

The third section will discuss the due process clauses of fifth and fourteenth amendments of the United States Constitution which serve as a particularly fertile field for developing the concepts of the rights of persons called mentally retarded. While several other constitutional law areas are serving as bases for legal action in the mental retardation area, the due process clauses seem to illustrate best the relationship between legal rights and social policy change.

The next section will give an overview of guardianship, one particular area of state law in which law reform efforts have closely paralleled changes in public policy and social perceptions of persons called mentally retarded.

THE NATURE AND ORIGIN OF RIGHTS

What is a "right?" What does it mean to "have rights?" What does "having rights" mean for persons society classifies as mentally retarded? When we look at the changing ways in which questions concerning rights have been answered over the years, what does this history say about the way that society perceives mentally retarded persons?

In one sense, a "right" is a legal power. To speak of the "right to vote," we mean that the law grants the authority to certain persons (citizens, over age eighteen, and so on) who meet certain conditions (residency, registration, and so on) to have their voices heard and counted in certain areas of social decision-making, governmental elections, or referenda. To have the right to vote does not mean that one is legally obligated to vote; in fact, any attempt at coercion by government or individuals in this country would be strictly illegal. The law has merely granted an individual that particular power.

From another point of view, the concept of "rights" means something quite different. To say that one person has the right to vote is also to say that all other persons and the government have a legal duty, at the minimum, not to interfere with that exercise in any way. In many ways, moreover, the government must provide opportunities and facilitate the exercise of the right to vote: for example, the location of polling places of registration must not prevent segments of the community from voting. Thus we might also say that a right is an expectation based on a shared standard that other persons will act or refrain from acting in certain ways. Some rights seem to focus almost entirely on the perspective of rights as authority or power. The right to practice one's religion, for example, does not depend on any state action. On the other hand, the right to education, for example, is based primarily on the expectation, justified by statutes and constitutional provisions, that the state must bring education equally to all potential recipients.

Where do rights come from? They derive from many sources. The sources of those rights derived not from governmental action, but from philosophical-religious mandates underlying our society are the most difficult to evaluate. Such human rights(or rights seen to derive from our humanness rather than from government action) are seldom defined or codified, but are seen as implicit in the development of civilization. Examples of generally accepted human rights are the right to have and raise children, the right to privacy, the right to a decent life.

A second source of legal rights is the Constitution, really a social-political contract or charter among persons establishing a government. This contract concerns the general relationship among the members and between the members and the government. In the Bill of Rights, and in numerous other sections of the Constitution of the United States, one can find many of the bases for civil rights—rights enforceable by and against governments.

Perhaps the greatest number of rights affecting our lives derive from the concrete and specific actions of legislatures in passing laws within the framework and scope of the enabling charter, the Constitution. Laws generally compel private individuals and the executive branch of the government to perform certain actions or to refrain from performing certain actions: to pay taxes, to provide medical services, or not to put other individuals at unreasonable risk, not to exclude a child from a regular school program without a hearing and showing of good cause.

The role of the judiciary—another major source of "rights" in the American system—is a complex and varying one. The legislature produces rules applicable to the population commonly and generally within the scope of the operating principles laid down for it by the Constitution. But the judiciary—usually acting within the context of a single direct clash between individuals, between governments, or between individuals and governments—interprets the rules and principles to resolve particular conflicts in the light of developing principles. Although legislation is usually quite general, one part of the mandate created by most pieces of legislation commands one or another executive branch agency to develop regulations to detail the law's operation. In most states, as well as in the federal government, regulations have the full force of law and are enforceable in court, subject only to a condition of consistency with constitutions and statues. Perhaps because of the distinctly undemocratic way that the executive branch as a whole is chosen (only the top few of thousands being elected) and because of the impact of regulations on society, many safeguards, usually embodied in state and federal administrative procedures acts, have been built into the process of regulation-making. Typically these include public notices, hearings, waiting periods, and so forth.

The last source of rights to be mentioned does not necessarily depend on government action. This is the contract, the mutual agreement between private citizens or citizens and government. The contract typically spells out the respective rights and responsibilities of the parties to it: whether to give to receive services or goods, or whether to do or refrain from some action in return for some other goods, service, action or anything of value.

ADVOCACY OF RIGHTS

Most of the trends noted above concerning developing and exercising rights have principally affected persons capable of advocating on their own behalf.

But what of those other persons who, for whatever reason or cause, are incapable or unwilling to advocate on their own behalf (or who are perceived as being incapable, which amounts to the same thing)? Does the concept of broadening responsibility and self-determination mean anything for a person unable to "self-advocate," unable to articulate his desires and interests sufficiently to trigger the legal responsibilities of those about him?

The notion of citizen advocacy responds partly to the needs of some mentally retarded persons for assistance in obtaining and exercising skills of self-advocacy or the right to responsibility. Although the advocacy terminology has by now been used in so many different contexts as to have lost much definitive meaning, one particular aspect of the notion deserves special note in this context: How does an individual (*any* individual—citizen, agency, professional, parent, attorney) determine the course of advocacy for an individual who has not expressed his interests and desires?

First, the advocate may choose to act in the "best interest" of client as "best interest" is articulated by another person—the family, friends, service workers, and so on, or a majority of these. Although this solution is probably the easiest—everybody has an opinion about what is best for his neighbor—it is also the most dangerous: it makes the advocate the agent of the sponsoring individual rather than of the client himself. It eliminates the independent monitoring-evaluation function that a true advocate can serve so well. Because the sponsoring individual is not disinterested, it is particularly risky: typically no advocate would be sought unless the sponsoring individual had already decided on a particular course regarding the client.

Second, the advocate may choose to act on the basis of certain articulated general assumptions, or principles of "best interest," such as "minimum necessary restriction," or "no deprivation without due process of law," or "equal protection," or "the most normal living and working environment possible," or "maximization of community integration," and so on. Even though this solution avoids the conflict of interest problem noted above, it raises a number of equally troublesome issues. Usually it is difficult to reconcile an approach based on general principles with another policy mandate in the field of mental retardation —individualization of services. Furthermore, when applied to particular circumstances, general principles often clash. For example, in a decision relating to the sterilization of mentally retarded young women, the human rights principle of the "right to family life" would clash with the similarly compelling equal protection principle of the "right of access to voluntary sterilization." In a decision relating to a prospective special class placement, the principle of the "right of access to an individually appropriate education" might clash with the "right not be denied access to regular education." In all such cases of "decision by principle," what principles are to be relied upon, and who chooses them? Although most might not object to the principles above, how will people react to the statement of "the greatest good for the greatest number" or "to each according to his productivity?"

Third, the advocate may choose to act on the basis of what he concludes he would himself do, were he the client. For most advocates these mental gymnastics would likely end in the determination that the advocate *would* do (and therefore that the client *should likewise do*) what the right, proper, or reasonable thing to do would be under the circumstances, even though the advocate, no less than any other human being, quite likely often acts in ways which are neither right, proper, nor reasonable. Should an advocate authorize drug experimentation with his client in an institution, just because such participation would be admirable and worthy?

This dilemma of advocacy on behalf of multiply-handicapped persons cannot be readily resolved, if desolvable at all. In the developing advocacy notion, this dilemma must be squarely and consciously addressed in every contact between the advocate and his client; and the advocate must evaluate his decision from as many perspectives as possible.

One further related dilemma of advocacy bears mention in this context. The advocacy terminology has come to describe many different kinds of relationships: citizen advocacy, professional advocacy, parental advocacy, corporate advocacy, legal advocacy, class advocacy, and so on. Applied with diligence and good will, all of these advocacies should, however, necessarily lead in the same preordained direction. Each form of advocacy mentioned carries with it the seeds of conflict or interest, because the citizens, professionals, parents, corporate organizations, attorneys, and classes have interests and perceptions of need which will conflict with those of the client. What action a parent, professional or organization will take regarding a client will always be colored by his or its own interests. A parent's decision regarding institutional placement will be influenced, for instance, by the interests of all the family members in addition to the interests of the child awaiting the placement decision. Decisions right for a class of persons cannot be expected to be right for every member of that class. For example, shifting resources from the large residential institutions to community programs may be the best general decision for the class of all persons requiring mental retardation services. But to advocate such a course is not clearly in the best interest of those members of the class who remain in the institution during the interim.

The foregoing examples are not meant to convey a distrust of the motives underlying varying advocacy approaches. But we should neither expect nor demand consistency among advocacy movements in the area of mental retardation; the future may well bring, on the contrary, a plurality and conflict of mental retardation advocacies which ultimately will prove vital and healthy.

DUE PROCESS AND THE RIGHTS OF RETARDED PERSONS

Where is the concept of the rights of mentally retarded persons going? One area of *constitutional* law seems to hold perhaps the greatest long-term hope for mentally retarded persons and the cause of their rights—the due process clause of the Fourteenth Amendment. This requires that no state deprive any person of life, liberty, or property without due process of law. The changing application of those brief words to persons classified as mentally retarded evidences the changing way that society, through the political mechanism of its courts, perceives these members. What does the clause mean? And what does it have to do with mental retardation?

First, the clause is directed specifically to action by states (action by the Federal government is already covered by the Fifth Amendment), and not to the action of private individuals. The doctrine of state action has, however, expanded greatly over the years and, although still in flux, today clearly includes the actions of persons acting "under color of" or under the apparent authority of state law, whether or not state law specifically authorizes actions. The doctrine also allows using state facilities, such as a court, to enforce a private claim, such as a restrictive covenant in a deed. Thus certain actions of parents and particularly of court-appointed guardians may be interpreted as state action in certain instances, as might the action of state agencies, private agencies which receive state licenses or support, and the courts. For example, action by a guardian in seeking to institutionalize, sterilize, or authorize medical experimentation upon his ward may be subject to constitutional limitation and control to the same extent that such actions by the state itself are subject to constitutional control.

The second point of interest in the due process clause relates to the term "deprive." The term reaches not only absolute and total deprivations, such a taking of property or liberty, but more limited incursions or restrictions as well. The state can deprive a person of property by restricting its use, just as it does by taking ownership of it outright. For example, the zoning of land, restricting the uses to which the owner may put the land, is a deprivation of property subject to due process guarantees of hearing, notice, and so forth, not unlike the actual taking of land by the state for conservation purposes, which taking is also protected by the clause.

Third, the concept of "liberty" in the clause has come to mean much more than the absence of criminal incarceration. Increasingly, the term has come to represent the basic freedoms of the Bill of Rights, as well as the right to choose and work at an occupation, the right to travel, the right to be free of social restriction (for example, segregation), and the right to be free of legal restriction (guardianship, criminal prosecutions not involving incarceration, and so on). The future may well bring an expansion of the liberty notion into other spheres of restriction, whether *physical* (for example, institutionalization, chemical or body restraints), *social* ("special education" placement), or *legal* (guardianship).

Fourth, the motive or intent behind the particular restriction is increasingly being shown to be irrelevant. Supreme Court cases concerning juvenile court law have clearly mandated an objective assessment of state activities which have the effect of restricting, whatever the label or underlying philosophy. That institutionalization may benefit the individual and not punish him for misbehavior makes the placement no less a deprivation of liberty. That a guardian seeks the sterilization of his ward for the best and most logical reasons may fall outside the scope of inquiry into the individual's rights to privacy and family life.

Finally, what does "due process" mean? Hundreds of scholarly works have intended to explicate these two words, but the basic concept can be summarized very briefly for this chapter's purposes: governmental action which affects individual liberties must conform to traditional notions of fundamental fairness. What is "fair" in the particular case depends on the historical importance of the liberty affected and on the scope and manner of the deprivation. For example, both murder trials and parking fine assessments are subject to due process protections, though fairness in the second situation dictates a much less comprehensive scheme than in the first. Furthermore, when the state is acting to restrict the individual for his own or the social good, the nature and duration of the restriction must bear some reasonable relation to the purpose of the confinement. The restriction must last for the shortest time and under the least restrictive conditions possible to accomplish the purpose of the restriction. When the classification of an individual leads to his restriction or other detriment, that classification and the means by which it is made must be rationally related to a legitimate state objective.

GUARDIANSHIP: A CASE EXAMPLE

An example of the traditionally restrictive-protective posture of the law and society toward mentally retarded persons is guardianship and legal competency. Essentially, guardianship is a legal device common in state law by which control of a person's property or of property and person is given to a second person, governmental agency, or private corporation. The person losing control is usually called the "ward," and the person getting it is called the "guardian," the "committee," the "conservator," or the "custodian," depending on the state.

Not just by chance can guardians typically be appointed only by a court, and not by an administrative agency. Despite the benign motives usually behind the appointment, it and the restriction it entails for the ward have traditionally been viewed as a deprivation of liberty and property sufficient to bring the appointment within the due process guarantee of the Fifth and Fourteenth Amendments.

Traditionally, guardianship has had absolutely nothing to do with helping or protecting the ward in any way. When the device arose centuries ago in England, its function was to preserve the property of minors whose fathers had died, solely for the ultimate benefit of the King. When most guardianship laws were enacted in the United States in the nineteenth century, the absence of a king obviously implied some other legal function for the device.

Modern guardianship is directed primarily at preserving funds and protecting persons other than the ward from the effects of the ward's indiscretions and inability to handle his money. Both the language of the statutes and the nature of the court cases have clarified these functions.

The effects of a guardianship appointment vary from state to state, but are always mainfold. Typically, in the process of the appointment, the ward is determined to be legally incompetent to handle his affairs. Thus, he may be legally incapable of making a binding contract, buying on credit, buying for cash, renting an apartment, obtaining employment, even opening a savings account, or giving away or selling either his property or items he has produced. Furthermore, he is made unable to change his residence, to refuse or seek placement in an institution or other facility, to refuse or seek medical treatment including sterilization and abortion, to refuse or seek being made a subject in medical experimentation, and so on. These are the direct results of the appointment.

Numerous indirect restrictions result as well. In Massachusetts an individual under guardianship cannot, under statute, vote. In some states, wards cannot [2] obtain driving licenses, cannot obtain automobile insurance even if they have a license, cannot marry. They cannot, in short, act to take control of their own lives and destinies. Thus, while the specifics of guardianship laws and cases vary from state to state, the overriding themes remain constant: enforced dependency, expectation of lack of change, overly generalized classification lacking any rational relationship to the nature of the individual's handicap, and a narrowly medical evaluation model.

From the point of view of social policy and mental retardation, guardianship statutes typically have three major flaws: first, their position regarding the need for guardianship and the powers of the guardian is strictly "all or nothing." If it is determined that the individual is wholly incapable of taking care of himself or his property, then a guardian is appointed who has the broad powers regarding the ward's future. Under these circumstances, the restriction, or "protection," of the ward is complete. On the other hand, if it is determined that the individual is *not* wholly incapable of caring for himself and his property, then a guardian is not appointed and the individual is wholly unrestricted—and wholly unprotected, regarding his person and property. Since very few mentally retarded persons require the total shelter of a full guardian and since a larger number of retarded adults may require some lesser degree of counsel, advice, and protection unavailable to them under existing guardianship laws, these laws do little good.

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[2] The use of the term "cannot" is admittedly an oversimplification for several reasons First, there is the traditional legal distinction between contracts which are "void"—without legal force from the onset—and those which are "voidable"—or valid until challenged. Second, legal incompetency is not absolutely determinative of the legal disqualifications of the individual under many of the listed circumstances. In many states, the fact of the appointment of a guardian is merely evidence of legal incapacity involving, for example, the making of a will. Third, several of the disqualifications listed involve the necessity of the individual under guardianship having to be identified as such before the disqualification is effective. Screening procedures for voting, for example, are sufficiently loose that many persons under guardianship may vote, the likelihood being that the issue of guardianship will not be raised unless the individual raises it himself. Nevertheless, the disqualifying nature of many of the guardianship statutes is the subject of this portion of the chapter, and the fact that the disqualification is incomplete does not diminish the negative aspect of the law.

As a second flaw, traditional guardianship laws assume that, once a guardian is appointed, nothing in the situation of the ward will change. Most statutes do permit a subsequent hearing to determine the continuing need for guardianship, but the ward alone must request the hearing and prove that the guardian is no longer needed. Once a person is placed in a situation of total dependency, such as guardianship, and kept there for a time, the self-advocacy which the statutes require is wholly unrealistic.

Although the basic difficulties remain, law reform efforts have progressed in lessening the impact of these flaws. Statutes in New York and Ohio[3] now require multidisciplinary determinations of the need for guardianship, as well as mandatory periodic reviews of its continuing need, and new limited restriction-protection levels of guardianship.

Furthermore, guardianship statutes typically require only the certification by a psychiatrist or other physician of the general clinical statuses listed in the statute, despite the fact that a person's being mentally retarded has nothing in itself to do with the need for guardianship.

In addition, except in the few states which authorize some variety of "agency guardianship," establishing the guardianship relationship depends on the existence of a volunteer guardian. For many mentally retarded citizens, particularly those institutionalized for a long time, no one may be willing to take on this role.

Where is the law headed with respect to guardianship and its numerous failings for mentally retarded persons? Slowly, current trends are indicating four basic shifts in the guardianship laws in several states.[4]

First, the law is dropping the presumption that mental retardation alone requires appointing a guardian. To justify appointing guardians for those few among mentally retarded persons really requiring this extreme protection, the law is now demanding multidisciplinary evaluations. These evaluations will tend to focus on the adaptive behavior of the individual in the community, rather than on the general medical-clinical categorization. Second, the law is slowly backtracking from the "either-or" character of present appointments and endeavoring to tailor the appointment more to the specific needs of the particular individual requiring guardianship. Third, the institution of guardianship will take on service-procurement and option-creation functions, with "estate preservation," the classical guardianship function, falling far into the background. Last, guardianship will be perceived not as a permanent relationship, but as a protective device brought on by social necessity for limited prestated purposes and for limited periods of time. The burden for justifying the continuing need of guardianship will never fall on the mentally retarded person himself, but on the guardian. Further, the decisions of the court and the guardian will be subject to formal periodic review. And most states will no longer authorize certain powers currently exercised or exercisable by guardians. Generally, these limitations will be in areas where vital interests of the ward are put in serious and long-term jeopardy and where objective decision-making on the part of the guardian is most difficult and usually based as much on general social factors as on considerations of the ward's welfare. Areas of traditional guardian-prerogative being curtailed include authorization of medical experimentation, particularly when unrelated to the individual's specific needs, sterilization, abortion, and institutionalization.

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[3] New York Surrogate's Court Procedure Act, SS 1750–1754; Ohio Revised Code, sections 5119.85–5119.89.

[4] Colorado, Massachusetts, Nebraska, New York and Ohio.

IMPLICATIONS FOR THE FUTURE

Based on where the law has been concerning the rights of mentally retarded persons and where it appears to be today, some forecasting of the future situation of the law seems warranted. These forecasts can be framed in terms of broad principles with implications for law reform, for the "helping professions," and for advocacy.

(1) The Liberty Principle: Any restriction of the individual is suspect, regardless of the nature, label, or motive of the restriction. Any restriction must be to the minimum degree necessary and for the shortest possible duration. Ultimately, none should be countenanced for any person, let alone any class of persons.

(2) The Self-Determination Principle: Advocacy ultimately aims to assist the individual to create and exercise options, within whatever capabilities he possesses.

(3) The Developmental Principle: An individual can grow; the function of advocacy should stimulate individual and social change and assist the individual and society in accommodating to this change.

(4) The Individualization Principle: All law and social policy is grounded on the individuality and the worth of each human being, regardless of his handicap.

In short, the law seems to be driving toward a goal of broadening the opportunities of every individual, regardless of handicap and allowing him as much responsibility for the course of his life as his inherent and learned capabilities permit. Therefore, advocacy must strive toward the enhancement and full use of this concept, this new right to responsibility.

CHAPTER V

THE GOAL OF INDEPENDENCE

by Jennifer Howse [1]

As a nation of pioneers we come from a tradition built on conquering new territory. Essential to the pioneer spirit is the will to set difficult and high-reaching goals and to apply human energy, time, and resources until the promised goal is achieved. This process has been repeated again and again in our history, and in most cases a goal, once established and agreed upon ,is accomplished. Examples of recent success in goal achievement can be found in the fields of aerospace, corporate industry, and military weapons development.

In human services the same pioneer spirit appears in national goals such as conquering polio and cancer, providing medical services and income maintenance for the poor, aged, and disabled, and equalizing educational opportunities for handicapped children.

The field of mental retardation is now responding to a national goal of deinstitutionalization. This goal mandates that the community should possess service programs which will eventually eliminate placing retarded individuals in state institutions. This goal also calls for returning mentally retarded individuals from large institutions to their respective communities.

A change in service location does not, however, necessarily guarantee greater well being. Concomitant with the goal of deinstitutionalization, current expectations about the potential of retarded persons must be examined: toward what ultimate state of well-being are retarded citizens being directed in the community? This most crucial question demands dramatic changes in the expectations of the public and of many persons in the field of retardation. These expectations concern the quality of life we allow ourselves to envision for the retarded. Stated in a different way, what dreams and plans do we have for those people on whose behalf we have chosen to advocate? What ultimate goal do we envision for retarded individuals?

An examination of many of today's institutional and community programs suggests that maintaining the status quo is about the extent of our vision. Using a status quo model of services has three major philosophical implications, all negative. The model's nature argues against change and development. Further, a status quo model nurtures a focus on disability, since the disability of retardation is the reason for providing services. Finally, for reasons of efficiency and economy the model allows for the fewest services to be delivered to large groups of institutionalized clients. Because a service system designed to maintain the status quo *will* maintain the status quo, this model of services dictates a goal of dependence for clients. Therefore, persons who ever needed services would always need them.

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[1] The author wishes to express her indebtedness to Mr. Kingsley Ross for many of the concepts in the paper.

If we are going to shed this entrapment which can occur just as well in a community setting as in an institutional setting, a new national goal must be shaped, articulated, and applied for retarded citizens. This goal must carry a new set of assumptions upon which to build a service delivery model, and it must point toward future actions and directions.

A NEW NATIONAL GOAL

What ultimate goal should we advocate for mentally retarded persons? *Independence.* The same independence we take for granted.

For us, such independence means being able to

- participate in a variety of physical activities and sports including swimming, bowling, volleyball, and skating
- eat our meals with relatives and friends in a family style atmosphere
- eat in a restaurant whenever we choose without receiving assistance in ordering and paying for our meals
- choose and purchase our own clothing and make decisions about appropriate sizes, color, style, and cost
- assume responsibility for paying our rent or mortgage
- pay federal, state and local taxes
- enter into relationships with others and have an opportunity to share feelings with friends
- work competitively with others in a factory, office, or work environment
- earn at least a minimum wage to be self-suporting
- use the public transportation available in our community
- plan for and take vacations
- know when to call a police officer for assistance

- arrange for medical and dental checkups when necessary and to provide for our own medication
- read newspapers, periodicals, and watch television news programs to follow current events.
- exercise our basic rights including the right to vote.

ACHIEVING A GOAL OF INDEPENDENCE FOR RETARDED INDIVIDUALS

If we adopt the proposed goal, we must also establish a method to account for the progress of retarded individuals toward the goal. This method must recognize that retarded individuals function at different levels of capacity for independence. These levels may range along a continuum from complete incapacity to a full capacity for independence.

Although these levels of capability are difficult to define, one can project a desired level of independence for any person in relation to his physical, economic, and social functioning.

(1) *Physical Functioning—Mobility:*

The fully capable mentally retarded person will independently use all available public and private transportation without assistance.

The less capable retarded person can use public and private transportation but may depend upon some occasional supervision and direction.

A person with quite limited capability can use public and private transportation with supervision.

The least capable retarded person can be helped to him use public and private transportation.

(2) *Economic Functioning—Work Skills:*

A fully capable retarded person can engage independently in competitive employment and earn a living wage.

The marginally capable retarded person can work in a sheltered employment situation and may earn a living wage.

A less capable retarded person can participate in work and earn some wages, depending on his productive ability, in a workshop or activity program.

The least capable retarded person can be helped to perform some rewarding tasks.

Such a classification allows one to identify distinctive levels of physical, social, and economic functioning among all mentally retarded persons. One must take into account these varying levels as starting points but must, at the same time, stress that almost any person's current level of functioning can develop toward a more independent level.

Accounting for an individual's progress toward the goal of independence must, however, occur in more detail than a simple assessment as above. An individual's current level of capacity for independence must be assessed in terms of the separate skills that constitute his current level of social, economic, and physical functioning. All three of those areas should be considered equally since they are interrelated and can all affect a person's ability to live independently.

Different levels of functioning may be viewed as a composite of a person's acquisition of certain skills. Therefore, to chart the movement of a retarded client from one level of functioning to the next, one must chart the existence and acquisition of certain skills. In this way one can develop and monitor a meaningful plan of service for each individual. Further, services provided to retarded clients can be accounted for in terms of what changes occur in the client.

After a person's level of functioning has been assessed, the skills he needs to function independently can be identified, and appropriate services to develop those skills may begin. Through this approach, one can identify and develop those social, economic, and physical skills necessary to move a person from a level of dependence, semi-dependence, or marginal independence to a level of complete independence.

STATE EFFORTS TO ACHIEVE THE GOAL OF INDEPENDENCE

Several states, including California, Florida,[2] and Nebraska, are currently trying various methods to measure the effect of services in changing client skills. The assessment efforts center on the concept that retarded persons need to acquire certain abilities to perform certain functions necessary for a successful existence in society. Therefore, a meaningful service program should identify the skills which a client lacks and develop those skills to the fullest extent possible. Inherent in the approach of each of these states is a goal of independence, and further, the implication of a developmental model. The California approach[3] was developed on the premise that current methods and standards of evaluating services for retarded persons are inadequate. These methods fail to specify whether a program successfully solves a specific problem and what progress the individual makes.

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[2] For information about the Florida model, write for "*The Directions for Florida's Retarded Citizens*", Division of Retardation, Florida Department of Health and Rehabilitative Services, Tallahassee, Florida.

The California method perceives mental retardation as a continuum of functioning ranging from complete dependency to independent functioning. Dependency is characterized by the need for total specialized services such as for profoundly retarded, non-ambulatory persons receiving 24-hour care in a state institution. The other end of the continuum is characterized by completely independent functioning which reveals no functional or behavioral difference between a person once identified as retarded and a "normal" person.

The California approach has attempted to identify those skills and functions necessary for independent functioning. These areas include self-help skills such as ambulation, eating, dressing, and personal hygiene; communication skills, community living skills such as money management, use of transportation, and participation in recreational activities; and behavior problems such as aggressive or destructive behavior, withdrawal, and excessive dependency.

By defining those skills necessary for independent functioning, this approach provides a method of setting goals for each retarded person and then of evaluating the results of program efforts. The skills necessary for independent living which an individual does not yet have can be identified, and goals for developing those skills can be established.

Nebraska has developed a smiliar approach to the evaluation of services provided for mentally retarded persons.[4] This approach is designed to measure how well the needs of clients are being met and to determine how well service providers are functioning.

The Nebraska method, like the California approach, defines those behaviors or skills necessary for independent living. These include self-management skills such as grooming, eating, and personal hygiene; communication skills, interpersonal skills such as group participation and interaction with others; environmental structuring skills such as meal preparation and money management; environmental access skills including using the telephone and public transportation, and employment skills including work quality and persistence.

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[3] The California method is called "Individualized Data Base," and information may be obtained by writing to Alan Boroskin, Ph.D., Pacific State Hospital Research Group, P.O. Box 100-R, Pomona, California, 91766.

[4] Community Regional Services developed the "Nebraska Client Progress System" under the direction of the State Office of Mental Retardation, Nebraska Department of Public Institutions, Lincoln, Nebraska.

This method assesses each person in terms of his ability to function in each of the areas defined as necessary for independent living. As a result of this assessment, the method identifies areas of need and begins appropriate programs to develop those skills. This approach can identify gaps in services and duplication of efforts and can objectively measure and evaluate the effect of programs on individuals.

IMPLICATIONS OF ADOPTING THE GOAL OF INDEPENDENCE

An approach which identifies and develops those skills necessary for independent living can help a retarded person toward the goal of independence. National adoption of this goal would affect the planning of services on federal and state levels and the delivery of services in local communities; most important, it would increase the ability of retarded individuals to participate as independent members of a community.

Deemphasis on the Need for Life Support Services. This approach would obviate programs which provide *only* life support services. Instead, all programs would aim toward growth and development of those skills necessary to achieve independence. For the retarded individual, this approach means that the services he receives will be designed to increase his level of functioning rather than maintain him on a certain and often permanent level of activity.

Reduction in the Labeling Process. An approach which assesses those criteria necessary to achieve independence does not use a relative IQ score to determine potential level of functioning. Instead, the method focuses primarily on those social, economic, and physical skills which individuals have or will need to achieve independence. Plans for a retarded person's future development will not be based on an IQ level, which often implies a static condition with negative expectations. Instead, each retarded person will be recognized as having varying degrees of abilities and having individual needs which can be developed to achieve independence.

Activation of a Developmental Model. Programs aimed at achieving independence use a developmental approach in providing services to mentally retarded persons. They will be viewed within a framework which recognizes and encourages the potential for growth. A dynamic and growth-oriented approach thus replaces traditional models which often implied inabilities and limitations. Such an approach will affect the way a retarded person views himself as well as the way family members and the general community perceive him. If an individual lacks certain skills to be independent, the approach aims to develop them so that the retarded person can achieve the highest level of independence.

Motivation and Direction for the Retarded Individual. An ultimate goal of independence can motivate and direct a retarded individual and lend a sense of purpose to his family and friends. The stated goal implies that retarded individuals can develop skills to live more independently if they receive appropriate resources. The goal clearly defines a purpose for each program and provides direction for our efforts. This clearly defined approach shows the retarded individual and his family the level on which he is functioning and what skills need to be developed for independence. Programs of services thus become more understandable and purposeful because the family and the individual know what they are working toward.

Recognition of Individual Competence. This approach replaces the more traditional attitude of incompetence associated with retarded persons and recognizes the abilities that a retarded person has or can develop. Thus, the adoption of this goal will replace a negative attitude with a growth-oriented one which leaves room for and indeed encourages active participation by the retarded person in decision-making.

IMPLICATIONS FOR COMMUNITY AGENCIES

An approach which can assess an individual's level of functioning and can identify those areas needing development to achieve independence has direct implications for community agencies involved in providing services to retarded persons. When one considers some of the constraints on serving individual clients, such an approach seems especially important.

These constraints mostly relate to the types of funding and to categorical resource allocation patterns that have emerged over the last decade. The current problem of resource allocation arises from the administrative realities of dealing with special target groups and the models that have evolved for categorical funding. For example, administrative reality may be based on population characteristics such as urban, rural, or suburban. But homogeneity of population characteristics does not mean a homogeneity of problems. Special problems associated with this model of reality are characterized as "ghetto" or rural-isolated, and service project funding depends on meeting the needs of individuals in these settings.

Income level of clients provides another type of administrative reality, because of the categorical emphasis on using funds for services to low-income clients. From this model arises a dual service system, especially in the area of medical services for clients who can afford medical treatment and those who cannot. Anyone who compares public health services to those offered by private physicians can see the inequality of this system.

Another type of administrative reality is based on neighborhood, city, or county boundaries or agency delineation of service areas or districts, in which these zones may impose criteria for eligibility for services.

Superimposed on these criteria for services are the types of constraints associated with the way agencies traditionally evaluate and account for services. Specifically, agencies account for services in terms of dollars spent, types of persons employed, types of facilities used, and number of clients served. Yet none of these indicators really identifies what happens to the client after he receives the service. The implementation of the goal of independence will affect the way a local agency assesses retarded persons, the method by which it provides services, and the manner in which agency efforts are evaluated.

Developing More Individualized Programs. To implement the goal of independence, community agencies will begin by assessing an individual's needs and the skills he requires to function independently. After identifying these needs, the local agencies can plan appropriate individual services aimed at developing skills. These services will recognize retarded persons as individuals with varying degrees of skills and provide for the development of abilities essential to independent living. Thus, the valuable services provided by the agency will be individualized services rather than broad, generalized programs directed at groups of clients.

Better Decision-Making Agency Administrators. This approach should allow administrators of community programs to make decisions more effectively, as they receive ongoing data relating to the individual client's needs and abilities. By being able to identify individual needs and progress, the administrator should be able to recognize gaps in programs and services. Therefore, he should be able to make more appropriate decisions about allocation of manpower and resources and the direction of future program development.

More Effective Evaluation Methods for Local Agencies. The method implied in the goal of independence for mentally retarded persons will require that agencies identify all measurable skills necessary for independent living. Evaluation of local program efforts will then focus on the number of individuals who have achieved independent living and the number of skills necessary for independent living which have been developed. Through this improved method of evaluation, program administrators can identify those areas of programs providing effective services and those areas not achieving their objectives. The improved method of evaluation will result in the development of improved services for retarded persons.

Clearer Direction for Local Agency Efforts. If a local agency adopts an ultimate goal of independence, it must objectively consider and plan individual programs and allocate its resources effectively so that it can carry out the programs. All programs will have a specific purpose and will be directed toward the same goal of achieving independence for retarded persons.

SUMMARY

We are currently responding to a national goal which calls for deinstitutionalizing retarded individuals and subsequently returning them to the community. No one can deny the importance of such a goal and its potential effect on the life of a retarded person. But this return to the community should be guided by the promise of new opportunities for positive growth and change for the individual. The goal of independence will afford such opportunities and can bring many positive results for program development, management, and evaluation. Through the skill assessment approach suggested earlier, information on each individual client can help in building individual prescriptions and managing programs. Further, programs can be evaluated in their most important dimensions: What changes are occurring in the client as a result of the program?

Above all, the goal of independence promises far-reaching benefits for the retarded persons themselves: Within a framework of independence the retarded person must be viewed as an individual with certain skills at his own level of competence who, like most of us, is working toward a goal that will bring about a better quality of life.

CHAPTER VI

A PARENT SPEAKS

by Lotte Moise

What made our small house in rural Western America into a home? What insights did we—a father, a mother, and three children—gain so that our home worked and we became a family that 'hangs together'?

Barbara, our third and handicapped child, contributed significantly to the subtle changes in our heads and hearts—changes which have taken twenty years to come into clear focus. When she was born we were a rather achievement-oriented, middle-class family. Intelligence was expected; stupidity was a dirty word. We were hardworking, super-responsible members of the community—never too busy to put up downtown Christmas decorations in a howling gale or preside over the PTA. Karen and David, at the ages of four and two, lived up to all our expectations in line with Gesell and Spock. Then Barbara was born and changed the tenor of our home. Karen was the first to voice her doubt when almost accusingly she asked me one day: "Why doesn't our baby DO anything? Keith (our friends' baby) rolled off the bed today." And this was the beginning of months and years of doubt, ("She'll be okay—My cousin didn't walk until she was three")—guilt ("Maybe that rash I had last year WAS German measles and I should have checked it out")—fear ("What will become of her when she grows up?")—resentment ("Why did this have to happen to us? I had such plans for our lives")—prayer ("Dear God, if only she'll learn to talk, please!").

There were times of terrible tension. While I was aware of Barbara's noticeable early deficits and was soon to be caught up in the rigid clinical prognoses of the early 1950s, Al, the papa, seemed to be dodging the problem by refusing to admit that anything was wrong. "Don't be nervous," he'd say, "she'll catch up if we work with her hard enough." I remember many a furious argument when I defended the reality of her physiological impairment and could see only limits in her future, while Al defended his irrational belief in unlimited potential. Barbara, in the meantime, responded to the warmth of his love and optimism and squirmed ecstatically whenever he came into her range of vision.

We luckily had good allies to help us over the rough spots. Our 'primary physician' was frank, warm, and supportive and we trusted him. Karen and David heard the simple advice of Barbara's pediatrician who said "Help your sister grow, but don't help her too much!"

Slowly at first, but accelerating all along, Barbara taught us to listen to and learn about her needs. Like a Jack-in-the-box she popped out of the confines of the 50-IQ trainable cubbyhole and blew all my neat professional pre-conceptions, labels, and limitations to the four winds. And with these restraints gone, I can now recognize the SIX R's which helped our house become a home.

RIGHT TO RESPECT

Respect means "value"—"to be worthy of esteem." Between mates in marriage it is considered a solid plank and a foregone conclusion. Respect can grow, even when passion and romantic love have cooled. But how about the children? Although we cuddle and love, bathe and feed, spank and tease, and play and help with homework, is it ever too early to express our respect for them?

Once I came into David's room and found him sitting, just sitting, on his bed and doing nothing at all when he was supposed to be changing his clothes. When I burst out angrily with my displeasure at his apparent laziness, he looked at me earnestly and said: "Mom, I need to have some time to think."

Karen, the A student, doggedly tried to overcome her poor natural coordination. Starting with her tiny two-year-sized tricycle, then stilts, later a bike, then tumbling, diving, and mastering her big stubborn horse, she irritated us to a point of anger with her persistence—until we recognized why and how valiantly she was striving.

I only hope that we spoke clearly of our respect to them, for all children need such solid stepping stones on their way to self-esteem.

Barbara's geared down rate of progress led us naturally from taken-for-granted high expectations to generous praise and applause. I still see her—age two years and three months, feet straddled wide, hands clutching the clips of her coveralls

—taking her first real steps. That and each new word in her limited vocabularly became causes for family celebration.

And from this we graduated to a dimension of respect which surprised us. We discovered that Barbara was aware of her handicap and that, if we truly respected her as a human being WITH her impairment, we owed her frank explanations and discussions of her handicap and its implications on her life. We also recognized that not long could she live her life as a girl without an awareness of boys and that true respect of her as a human being would grant her the right to a heterosexual life.

REGARD FOR OPINION

Regard for differences of opinion was not easily come by in our marriage. Broad areas of agreement existed in our relationship, such as in politics, money management, and music; BUT we disagreed on such sensitive issues as whether claiming a veteran's exemption is honorable or whether children must eat hot oatmeal every morning. At first we thought we must present a united front to our children on all issues, and we expected them to echo our opinions in important matters.

SHOCK! They didn't. David, the product of two parents who had taken an active part in World War II, was an avowed pacifist at age eight, and at ten he caused a hot discussion around the supper table when he challenged the value of daily pledging allegiance to the flag. Differences of opinion became the order of the day during the children's adolescence and ranged from hitchhiking to hotpants, from beards to booze. Then we began to recognize that home is a good place to air your views, be they ever so outrageous and shocking. Barbara soon joined the dissonant chorus by balking at baths, wanting to grow her hair long, and stating that she hated school and home. Gradually we began to hear each other out—to listen—and to accept. As we heard our children's different opinions on a variety of subjects, we learned that they were indeed widely differing people and that we had to prepare them for life in an ever-shrinking world of infinite variety.

Many "normal" young people came to our "Youth Hostel" during those years. It soon became apparent that these visitors did great things for Barbara's self-esteem, for she felt one of them. Many young people became profoundly moved by her, and some chose to enter a field of human services.

ROOM FOR DIFFERENCE

Our home was well regulated during the children's early years—regular naps, regular chores, much urging on regular elimination, and almost iron-clad bedtime hours on school nights —until Barbara came along. She seemed to crave irregularity and noticeably blossomed whenever we packed her with us to a potluck supper or school program. Late bedtime hours and strenuous trips seemed to spurt her rate of growth, and in this way we began an informal program of "infant stimulation." It was scanty and haphazard. At times the busy mother of a three and a five-year-old was glad of her quiet child. Looking back on those years I wish that Barbara could have had then the kind of preschool program we can provide now. We also stumbled onto an awareness which I now recognize as a "developmental profile." While she was slow at gross motor skills such as crawling and walking, she did an excellent job of feeding herself at an early age, and she had an uncanny understanding of complicated record players and operated them more competently than her sister. She spoke late and unclearly for years, but had a highly developed sensitivity for people's moods, and a startling extra-sensory quality. As we reinforced her assets to bridge the gaps of her deficits, we grew in tolerance of each other's short suits. It became acceptable for Mom to be poor at sewing and dense at threading movie projectors. Karen was rated as sloppy, but a venturesome cook. David's spelling was purely phonetic, but he was a fine mechanic. Father—well —father remained 'perfect'! Our house—furnished in a variety of styles, textures, and colors—was beginning to have space for different people, too.

RISK-TAKING

On the day Karen climbed up a tall slide for the first time, I experienced my first pain of risk-taking. At the bottom I could support her. Then she was out of my reach. She teetered on the top rung—then sat and looked fearfully the long distance down —then back at me. I would have climbed up and brought her down again, but already other children were impatiently waiting for their turn. So down she slid. Triumph reigned, and I knew then that other moments just like this one were waiting for me.

There were many. She and her brother left for kindergarten—they spent a first night with a friend—rode a Greyhound bus alone—went on their first date in a car—got drivers' licenses. What made it so much harder to watch Barbara take chances? Since "normal" children had conditioned us to success, Barbara's diagnosis of mental retardation had scared us into expecting failure. Once we recognized that risk-taking is essential for learning, we were better able to let go. So she learned to light her father's pipe and later the fire in the grate. To go on errands to the neighbor and later on the Greyhound bus. She swims in deep water and pours hot coffee. More nerve-racking learnings, such as crossing busy intersections and riding escalators, we delegated to someone less personally involved. Of course we worry that someone might hurt her feelings, cheat her when she shops, or take advantage of her trusting affection; but we also recognize that we cannot let OUR worry become HER straightjacket—that we must not cheat her of her right to failure, which is as integral a component of growth as is success. For Barbara was learning about freedom and the risks it entails. She most clearly expressed her own feelings about this when she was sixteen. A friend of the family had died, and it was a first and very upsetting experience for Barbara. We explained as well as we could and hoped that she was feeling better. A few weeks later she and I were having a round-and-round. I nagged. She balked, and suddenly she looked at me and asked: "When are you going to die, Mummy?" I was shocked. She was worrying about the one condition which we cannot change for our handicapped children. As I put my arms around her shoulder, I assured her that I was feeling fine and should be good for a long, long time—"But why do you ask, Barbara?" Her answer was: "Because then I will be free . . ."

RESPONSIBILITY

RESPONSIBILITY was an "all-cap" word in our household. It applied to daily school attendance, Sunday School, scout meetings, and concerts. A promise meant total commitment. We expected our children to abide by our standards of responsibility. In desperation David once turned to his father and said: "But what if I don't WANT to grow up to be as good as you, Dad!"—and with that we realized that a sense of responsibility must be learned and cannot be dictated. Everyone must experience the consequences of irresponsibility in order to opt for the opposite.

Of course we were overwhelmingly concerned that Barbara learn responsible and appropriate behavior in the framework of our home, and gradually she did. At first she was clumsy and destructive. Favorite trucks lost wheels. Dolls found themselves decapitated and card games disappeared. It was difficult to referee between irate "normal" older brother or sister who took care of their possessions, and their young retarded sister who was exploring with a vengeance. Later she learned to leave their things along; and although she occasionally still probes the innards of her transistor radio, she is generally better organized with her personal belongings than the rest of the family.

No secret formula aided this learning process. She was exposed to the same group dynamics as were her brother and sister. We praised and scolded, rewarded and punished, hugged and spanked. We learned that many concepts needed to be explained with greater patience and in great detail. Flip answers instead of the 'honest truth' had to be dealt with, and still do. The need for an occasional 'white lie' as opposed to a 'black lie' was hard to explain.

Becoming responsible involves many small steps. From individual tasks such as personal cleanliness, taking messages, and wrapping presents, she has had to learn to take part in group-oriented tasks such as folding clothes, washing dishes and dusting. She is not much of a self-starter yet, but is becoming more aware of her responsibility toward the group she lives and works with.

When she was little, liquor and sex loomed as tremendous worries on the horizon of her adulthood. But the first time she observed a drunk in a downtown gutter, she commented aptly, and she herself has decided to turn down alcoholic drinks in favor of diet cokes. She learned about sex in our home in the same way in which we all learned—by asking questions and getting straightforward answers, by observing animals and humans, and by watching television. She is well able to express one of the most basic of all human needs: to have a person to love her for herself—just the way she is—and she thinks well enough of herself to expect that some day this will happen. Our goal and hope for her is that she could hold up her end of a one-to-one relationship, be that in friendship or in marriage.

READINESS FOR ROLE CHANGES

We had a letter from our son recently. "Dear Al and Lotte," it began, as he told us his latest news. Then came a subtle switch. "Could you do me a favor, Mom, and look for something in my closet, please." The twenty-two-year-old young man, very much his father's respected colleague and his mother's friend, had unconsciously slipped into a former, more dependent role, where he called me Mom and asked for help.

The see-saw patterns of maturity and childishness are strangely unpredictable. Transition from childhood and dependence to adulthood and independence, later to old age and a return to increased dependence, rarely happens smoothly. Yesterday the children piled into our bed to snuggle. Today they pull away from hugs and kisses. A few days ago the child bristled at Mom's insistence that she wear snowpants. Today SHE wants pantihose and claims that her legs are cold. Small bids for adult status may alternate with regression into childish behavior, but overall most children dream of becoming grown-ups, and mentally retarded children are no different.

Barbara longed for THE status symbol of maturity, her monthly period, when she was only eleven. She could hardly wait to be eligible for Aid to the Totally Disabled at eighteen; and when we asked: "Why are you so anxious?" she informed us that she could then help pay for her sister's hospital bill. She would be proud to have her own money. The acquisition of a non-driver identification card was also a source of tremendous pride to her. With Karen and David we expected adulthood, but with our handicapped child it took jolt after little jolt to shake us out of our overprotective parental attitudes.

One day, about a year ago, Barbara complained of a little headache. "Want to take an aspirin?" I asked. "I already did," she replied, and with that I jumped all over her. "Don't you remember," I bellowed, "that we have a rule in this house that you must NEVER take any medicine without asking?" Her lower lip drooped. "But I KNOW aspirin"—and she promptly went to show me the bottle. I suddenly thought of three things at once: "My child is eighteen and a young adult. During our visit to Denmark where Barbara lived in a group home for a month, the director told us that all her mentally retarded residents learn to take their own medicine. And here we are planning to let Barbara move away from home, while I can't unlearn my 'mother' role."

I apologized to Barbara: "We will have a new rule now—a rule for young adults—who KNOW aspirin."

At this point you may say "yes, but . . . my problems are quite different"—and right you are. I have no illusion that our family's SIX R's—the six principles which seem to have worked for us—will magically turn into a blueprint for homes for all families with a handicapped child. It would be smug and simplistic to assume that I have given all the answers.

Some families appear to have the same resources—access to schools, counselors, medical services, and supportive neighbors—and yet can't make it. Marriages have split over a mentally retarded child. Parents have abandoned children in state hospitals or placed them in foster homes and rarely visited them. Some capable young retarded ladies are not allowed to walk alone to the corner mailbox. I know men and women who may not hold hands. Some parents forbid their adult sons to have a beer. One mother found it so overwhelmingly difficult to teach her retarded daughter to use a knife and fork that for years she took her to the corner lunchcounter and ordered a hamburger and malted milk for her supper. As a result, this girl's teeth are in terrible condition. I knew a young man with Down's Syndrome whose mother did not let him go to school, and every time we approached her she wept. Another young man has never gone to summer camp because his mother fears that he might go into insulin shock. Her only other child—a talented older sister—died of diabetes complications. I remember urging one father to allow us to refer his young son for a tonsillectomy and adenoid operation. The boy had significant hearing loss in both ears, and the physician warned that it would get worse. The father ran me off his land with a shotgun. Recently an elderly mother, herself in a nursing home, refused to give permission for her adult son to leave the State Hospital and move into a community that offers fine homes and support programs for its handicapped citizens.

Why is it that similar problems challenge some families and defeat others? And granted that it is so, how can we solve the problems resulting from the past and prevent new ones from arising? De we label families with problems "failures" and categorically place their children into community group homes, or can we help these families view their human experience of fear and fatigue in another light? Unfortunately, as Virgina Satir observes: "Family life is something like an iceberg. Most people are aware of only about one-tenth of what is going on." Perhaps the parents' inability to ask for help or respite, their unwillingness to let their handicapped child off the "short leash" of dependence, their need to perpetuate their disabled son or daughter in a retarded or sick or eternal child role is due to a very private need of their own. Perhaps with counsel and support they can reevaluate their home in the light of these unmet needs. The discovery of the cause of their own hurt feelings and fears may unleash new energies and the capacity of coping with the presence of a handicapped family member.

That not every family will cope in the same manner is essential to our American tradition. People feel that they have the right to raise their kids the way they want. Although it may have served our pioneer forefathers better than it does us now, rugged individualism is still held in high esteen. While in some areas of the world handicapped children are registered at birth, then followed up, treated, and provided habilitative programs by Government, we must first create family understanding of handicaps by public education and awareness. I believe such awareness is well worth pursuing and will result in full citizen status for our children.

PART 3

HOME AND COMMUNITY

CHAPTER VII

WHAT IS A HOME?

by Lotte Moise

What types of homes do we envision in our communities for families with handicapped children or adults? Successful homes for developmentally disabled persons already exist, scattered across this country and throughout the world. They come in different sizes and for persons of different ages with varying degrees of handicap. Guidelines and evaluation tools are available.[1] Now we must begin to close the gap between dreams, scattered experiments, models, or plans—and real needs. If we will stimulate public awareness, generate public support, and demand public funds, we can have good community homes for all persons who need them.

Each community—be it a city, a county, a rural region—must prepare homes for a variety of people, based on a continuum of growth and development. If we see handicapped persons as developing human beings, then they clearly do not need a "lifetime residence." We don't expect our normal children to mark time in the same place. In fact they often hope, "Some day I'll get away from here to a place of my own," a hope which carries them through some rough spots. The disabled child has the same need to be assured that he will grow up—and away. His home must be a rung on a ladder leading to higher levels of achievement, self-esteem, and independence. For example, when I asked our daughter Barbara for her definition of a home, she said, "Home is a moving out."

The home must help young persons become as independent as possible. One of the first surprises of the Danish group home in which Barbara spent a month came on the first day. They handed her a key to the front door! A key is a symbol of adulthood. In the Danish hostel each severely retarded young adult is awarded a room key as soon as he can manipulate it.

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[1] Some of these have been published by the Accreditation Council for Accreditation Council for Facilities for the Mentally Retarded in Chicago and the National Institute on Mental Retardation in Toronto.

Our next surprise was the fact that this group home in central Copenhagen was a three-story house, and the back stairs were steep and winding. In no time at all our fearful, awkward gal, raised in a groundlevel California house, learned to negotiate them—not one foot at a time, but with alternate feet, and even carrying something in her hand. Risk-taking does pay off. In contrast, when the family care home where she was staying in California was checked out for certification requirements, the official requested that horizontal shelves be placed in the glass panels on each side of the front door. These panels were about eight inches wide, and there was no way in which our husky 180-pound, 5 ft. 7 in. daughter could have fallen through them. Part of our overall public awareness energy needs to be directed at fire and licensing regulations on state and national levels.

SIZE OF HOMES

In addition to developing homes which allow for the growth and independence of residents, what are some of the other common and distinctive characteristics of good community homes? The first important factor is the size of the home. We are trying to integrate our handicapped friends and their homes into neighborhoods—yours and mine—so one of the base requirements for every kind of group home is *small size*. Experience has shown that the growth and development—the integration into the community and the acceptance by neighbors of the handicapped person—happen more successfully in a moderate-sized house than in a junior institution. In many cases, a normal house in a typical neighborhood can be adapted to its new role with minor changes.

The number of residents cannot be an absolute figure. It may mean two children to one family and six to another. The potential residents of the homes may have varying preferences regarding size also. Ann Shearer of Great Britain's Campaign for the Mentally Handicapped tells of the conference which was organized to consult mentally retarded young adults about homes. At the time the Government was planning for twenty in each residence. The conference participants overwhelmingly felt that this was too large a number and opted for six.

LOCATION

Location of the residence is the next important consideration. The home must be close to the mainstream of the community. I know a group of young people who live in a luxurious ranchstyle house overlooking the ocean—about ten miles from a small town. There is no public transportation, and the road is too dangerously curvy, narrow, and heavily traveled for safe walking. Their work consists of making gift items in the back of a little downtown store. The seven young men and women represent a wide variety of interests and abilities, but they can only get to and from town "in lock-step" via their large stationwagon. How much better for their individual growth if they could learn to navigate on their own—to church or to a movie or to shop. If they lived close to town they could learn to return home in time for meals or to find their way to new parts of town. This kind of risk-taking could pay off in increased independence.

In Denmark one hospital for severely retarded residents is located right along one of the main thoroughfares of Copenhagen. They are allowed to roam all over their 'campus' without restraints. There are no gates or locked buildings. "We haven't lost one yet," was the answer to my concerned inquiry about their amazing mobility. "Mealtime always seems to bring them back!" I am convinced that the only way in which a handicapped person can learn his neighborhood is by exploring it—just like everyone else. This does not mean that the handicapped person, any more than the normal person, can do what he likes without regard for safety. He too can be hit by a car or drown if he goes swimming. It does mean that we must help him develop the ability to make choices and then be ready to accept the risk of these choices.

ROOMS AND FURNITURE

For the handicapped infant and small child, the group home must be a *home*. There should be a crib for sleeping and a playpen to want out of, a highchair to be fed in and to throw food and spoons from when that time comes. There must be a sturdy children's record player and a beat-up old piano, and just ordinary furniture which can handle an occasional natural accident. There should be a nice safely enclosed yard with fascinating things in it like rubber tires and a sandbox and perhaps a swing or a slide—a balancing bar and an obstacle or two.

The balance between sleeping rooms and living areas depends very much on the location of the home and the age and condition of the residents. A home in the country, in a moderate climate, can rely more on the outdoors than can a house in town. Little children tend to use their bedrooms mostly for sleeping and require more play space in the living area of the house. Therefore infants and children can share a smaller bedroom with two or three others, provided there is a large rumpus room with toys, physical therapy equipment, and a television. For the protection of adults and other children in the family, a quiet room should be reserved for reading or visiting. This arrangement shifts where the residents are adolescents or adults. Then the young person must have a choice in the number of roommates, and the bedroom will become a place in which to spend more time. The young adult may want to save allowance money or workshop earnings to buy a TV or stereo for his room.

The young person's bedroom (whether it is for one, two, or perhaps even three people) should be a retreat. Silence is a valuable commodity in any busy household. Privacy is everybody's right; and with adolescents and young adults, the rest of the household may need a closed door as protection from pop records. So each room must have a door and a lock, even if it's the kind that can be opened with a screwdriver from the outside.

The furniture need not differ from that of any other teenager's. If the bedroom is to be used as a sittingroom some of the time, a bed which converts into a couch is nice. Since she was young, Barbara has had to make her bed, change sheets (with help at first), fold and put away clothes into her own dresser. She has her own desk and used to have a children's phonograph in her room. To be able to take pride in their rooms the residents of a home should have a say in arranging their furniture. Individuality should be valued above conformity. Wall decorations may have a tendency to get a bit flashy during the pin-up and poster stage; but with a little guidance, sanity and good taste will prevail in the end. In Barbara's current residence the walls of the girls' bedrooms were recently painted, and the staff have ruled that nothing shall be placed on them. How easy it would be to mount a couple of large cork boards so that they could put up pictures of their families, postcards from friends, or other bright treasures.

Using a bathroom is one of the most basic self-help skills, and this room will continue to be important as the adolescent learns to take pride in his appearance. The number of residents per bathroom certainly depends on circumstances and economics. In our own home the bathroom was off a central hallway; and when the children were small, we had just one for five of us. In Barbara's current residence, six girls in three bedrooms use one upstairs bathroom, but there is an additional toilet downstairs. This kind of sharing can provide training in patience and consideration. In fact, the personal interaction and character training of a busy bathroom in the early morning hours is invaluable. Unless the developmentally disabled resident has specific physically handicapping conditions, he or she does not need a private bathroom. Sometimes a partition around the toilet can allow another person to use the tub or shower at the same time. All bathrooms should have locks, and each resident must have a shelf or cubbyhole for his own potions and lotions and a rod for his washcloth and towel. I believe that it is part of training in responsible behavior to learn to handle simple first aid equipment and household remedies. A special shelf can contain bandaids, cough medicine, ear drops, kaopectate, milk of magnesia, and aspirin. Training in this aspect of responsible health care can be adjusted according to the age, maturity, and ability of the residents and will prepare them for adulthood when they may need to cope with more important medications.

The kitchen is probably the next most popular room in any house. Again there is no need for special institutional equipment although commercial mixers are fun to have in any home where there's lots of baking. Perhaps electric ranges are safer than gas, but rules can be made and enforced about who may strike matches, and when, and where. A broiler is a potentially dangerous piece of equipment, but parents and staff can establish the time for learning its use. Just as tiny toddlers and their mothers have to learn to avoid the back hinges of heavy refrigerator doors, so the person who is retarded can learn about burners and ovens.

Residents should have free access to the kitchen in spite of the high cost of food. Refrigerators are tempting treasure troves to most people, and padlocking them doesn't solve the overeating problem. Good nutrition, balanced meals and sensible snack habits are learned better when there is well-guided access to the refrigerator. Meals should be a fun time, and a large diningroom table can set a family of almost any size up to twelve. We started our family with good plastic tableware.

Later they learned to handle pottery and china with kid gloves—Barbara too.

THE RIGHT TO INDIVIDUAL LIFESTYLES

Furnishings for all of these homes will be as varied as the people who reside in them. Houseparents and residents come in all sizes, colors, styles, and textures; and homes can reflect styles and lifestyles from Danish Modern to Grand Rapids. Some residences in Denmark are models of elegance and good taste, and reflect their attitude that "nothing is too good for mentally retarded people," but even the Danes sometimes wondered how these beautiful new quarters might look a year later. Actually, the residents took such pride in their surroundings and possessions that they reached unexpected heights of care and responsibility. We talk of the retarded person's rights to education, rehabilitation, and treatment. Let's not forget their right to an individual lifestyle: neat or messy, chic or funky, straight or groovy, energetic or lazy—a little of all of these things, but not cut from the same piece of cloth, poured into one mold, all in a row! Homes must have rules and chores, of course, but all rules should allow for exceptions like sleeping late on weekends, not making your bed once in a while, or eating breakfast in your bathrobe.

It came as a surprise to me, sometime during Barbara's teens, that she did not always want to accompany me. Somehow I had no faith in her ability to stay at home alone, although she could answer and dial the phone and take simple messages. I worried about the woodstove; I worried about intruders. One day I was nagging her to come along when she exclaimed: "I wanna stay home, Mummy. I want my peace!" She had to tell me how comfortable it feels to be alone in one's house which is temporarily quiet and empty. Each home must recognize this need for privacy and the sort of "space" which has nothing to do with square footage, but rather with the right to be oneself. And this right also belongs to our more severely retarded fellow citizens and can and must be expressed in their homes. Even the most severely handicapped person should live close to the community where he can enjoy the stimulation, warmth, and companionship of family and frriends.

Our local convalescent hospital recently accepted a profoundly retarded young lady of 20 whose mother requested her transfer from a large state hospital. Angela had spent all of her life in a crib. At the Convalescent Hospital they lowered the crib bars and let her play on a pad on the floor. Soon she was crawling, then walking with help. The old folks kept track of her when she headed for the front door. Angela's mother came every day to help feed her the main meal. She learned to hold a spoon and feed herself; and after a while she slept in a regular bed, all night long, for the first time of her life. Even the maximum care which someone like Angela needs, can be given better in a less institutionalized setting.

Model programs of integrated apartments, for severely disabled persons exist in Sweden—with England, Canada, Germany, and Holland planning similar projects. A Swedish nongovernmental organization, the Fokus Society,[1] provides specially designed apartments—modified slightly from surrounding apartments for 'normal' tenants. Most of the Fokus tenants are wheelchair bound. Seventy percent need help with dressing and going to the bathroom. Thirty percent have to be fed. Twenty-five percent have to be turned over in bed during the night. Most of them have other than physical handicaps. But in spite of the severity of their disability these people have been allowed to choose their lifestyle. The project provides special personnel and transportation, so that they can enjoy mobility and have access to work and social activities. Those who have ventured out of their protective nursing homes find dignity in being useful members of society. Return to the mainstream of life results in incredible developmental progress.

This return to the mainstream can only happen if we orient the home outward at all times. Residents must have the opportunity to venture forth and meet people on their own, not in a cluster or well-chaperoned group. For short-term intensive training, adolescent group homes may have boys or girls only. In that case friendships with members of the opposite sex must be encouraged and sex education provided. A sense of responsibility does not happen overnight on one's eighteenth birthday. The component skills of choosing, judging, planning, and deciding must be fostered over many years of sensitive, listening, non-judgmental houseparents.

Only a broad base of staff persons can make a system of residences work. Parents of disabled children will rest well only when they are assured of a continuing system of community residences, which, like our schools, come with a supply of motivated, well-trained, adequately paid, and sympathetic staff people.

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[1] Brattgard, Sven-Olof, "Integrated Living for the Severely Disabled," in *Models of Service for the Multi-Handicapped Adult*, New York: United Cerebral Palsy of New York, 1973.

For people are at the core of every home—people and their attitudes toward each other. Kahlil Gibran in "The Prophet" speaks straight to the residents of each community's homes for developmentally disabled persons. When he was asked to "Speak To Us of Houses," he said:

"Your house is your larger body,
In their fear your forefathers gathered you too near together,
And that fear shall endure a little longer.
Your house shall not be an anchor but a mast.
You shall not fold your wings that you may pass through doors, nor band your heads that they strike not against a ceiling, not fear to breathe lest walls should crack and fall down
You shall not swell in tombs made by the dead for the living."

CHAPTER VIII

CREATING COMMUNITY HOMES

by Nathan Newman

The right to live within one's own community and in facilities which offer access to good programs as well as adequate care is essential to growth and dignity. Adequate community residential services can allow a person to remain within his own community. The concept of the handicapped individual's living in the community as close to his natural home as possible implies the concept of the community as the focal point for the delivery of care, treatment, education, and recreation services. The first concept cannot easily be achieved without the second.

The overriding goal of all residential programs should be to allow the greatest possible flexibility so that the citizens, retarded or not, can make the greatest developmental gains. A variety of residential options must be available to fit the individual requirements of each child or adult. The retarded person should not be forced into programs which fail to meet his needs, and if an individual can no longer profit from the residential program, he must be provided with a route out of the system.

THE FACILITIES

For this chapter, a community residential service can be defined as a community-based housing facility, other than the individual's natural home, which affords living experiences appropriate to the current functioning level of the individual. It also offers needed supportive programs to maintain his placement within the facility and to assist him in achieving his potential. Many types of residential facilities are possible, ranging from the single apartment not tied to any service or supervisory pattern to specialized facilities providing a program of intensive rehabilitation or behavior modification. Some of these facilities may be group homes; others may combine overnight care and daytime programs attended by other residents within the community. Still others may be apartment complexes for those individuals who require little or no supervision.

The philosophy that normal patterns and conditions should be available to retarded persons should govern the establishment of the facilities. One means to achieve this is through the strategic location of residential facilities. The area should provide opportunities to use a variety of other public centers for shopping, entertainment, recreation, and other growth-stimulating experiences. In this manner, a person can learn the daily tasks essential to his increasing independence. As the person expands his world of interaction he needs to learn how to move throughout the larger community, gaining greater autonomy and testing his abilities by increasing independence within specialized facilities for the same reason that the less handicapped person requires it. He should be able to wear appropriate clothing of the correct size and some semblance of style, maintained in the same manner that other persons keep their clothes. He should be allowed to participate in self feeding and toilet training programs which will add to their dignity and independence. He should receive social experiences outside of the facility to help their growth and development. He can go on shopping trips, field trips to the beach, mountains, park, drives to visit family or friends, and so on. A severe handicap should not mean isolation. By helping the individual in these and similar ways, we create new perceptions for ourselves and others regarding the potential of all persons, while continuing to make available every opportunity for individual development.

PROTECTIVE LAWS

Each citizen within the community has a right to protection from harm. Whether retarded or non-retarded, handicapped or non-handicapped, every individual must be assured that his safety and security is considered a high priority. In safeguarding the community's well-being, the provisions within protective laws that relate to fire, safety, and health standards are important.

The appearance of the facility should conform with other homes in the neighborhood. The physical structure should in no way isolate the residence from others in the neighborhood. A community is more likely to respond favorably to residential facilities which do not contrast dramatically with other residential structures. Architectural design must help the facility blend into the neighborhood.

For retarded persons to fit into society, we must expose them to a "normal" life style. Any living facility should establish a setting which allows a normal rhythm of the day: awakening, eating meals, working, and sleeping at the same times as other members in our society. A facility should establish a normal rhythm for the week: leaving the place of residence to go to work, to school, to recreational activities, and so on, the same as the rest of society. This implies a separation of functions, because it is *not* normal in our society for people to live and work in the same setting or to spend all of their leisure time in their residences.

Only a carefully considered program can prevent a residential facility from becoming a large, impersonal quasi-institution with restrictions and fixed patterns of services. A facility must give persons with severe handicaps a sense of being persons. Respect for their feelings must be developed.

Many groups who have developed community residential facilities in the past have encountered their greatest problems around licensing requirements, zoning regulations, and safety codes. Restrictions which run counter to normalized living should be challenged. Retarded persons must not be singled out as a special group requiring stricter enforcement of these regulations. Unfortunately, communities often misuse zoning regulations to exclude persons seen as detrimental to the community's way of life or its property values; these regulations are often enforced only at the pleasure of the neighborhood residents.

The public must be properly prepared to support residential programs, so that the chances of arbitrary enforcement of restrictive standards may be reduced. To do this, a concerned group may distribute clearly worded educational material that spells out facts about retarded persons and the residential program. Informal "town hall" meetings can allow the public to ask questions and receive responsible answers.

STAFFING

The number and types of staff necessary in residential facilities will vary, depending upon the particular program and the individual needs of the residents. In some cases, a houseparent or housecouple might suffice, while in other cases, a social worker or educator may be involved as well. Some cases may require no houseparents or staff on a 24-hour basis (such as in cooperative apartment complexes).

Retarded citizens living away from their own homes need the experience of personal relationships, but the emphasis and significance of these relationships will differ for each person according to his or her needs. The staff must possess the human qualities necessary to engage each resident in a personal relationship which brings a sense of worth, dignity, and self-confidence, thus helping him toward emotional maturity. In the course of their homemaking duties, the staff members must be aware of and respond to the resident's emotional development and his physical, recreational, and educational needs. They must also recognize the resident's need to form relationships outside the facility, and they should encourage the resident to do so whenever the occasion arises. Furthermore, the staff must understand that the retarded person has the right to *choose* the person with whom he wishes to develop a relationship. Programs should select staff members who are responsive to the needs of the residents and the goals of their home. Their attitudes must stress the goals of integration, social acceptance, integrity, and dignity. They should be well-motivated and trained, adequately paid, and sympathetic. Some of the criteria which might be used in selecting staff include:

> *Persons active in community affairs.* They provide an ongoing contact and informal communication network with the larger community. This type of social interaction represents a powerful and constructive public education technique. A well-informed and socially responsive community will often guarantee the autonomy and stability so necessary to the long-term success of the residential services program.
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> *Persons with exposure to the social welfare community.* They can assist the residents in using service systems within the community. They should be familiar with the requirements and processes necessary for the residents to receive services.
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> *Persons who have practical experience working with handicapped individuals or who have had handicapped relatives or friends.* These persons are often equipped with a special understanding and sensitivity, difficult for professional persons with limited experience to grasp.
>
> *Persons with respectful attitudes toward retarded persons.* No individual can develop in an atmosphere which is

rejecting, stifling, or dehumanizing. The staff must be able to accept the retarded person as an individual and treat him with the respect due all persons and so essential to self-concept and dignity. Affording dignity means recognizing and respecting the individual's rights and his capacity for self-direction to the greatest extent possible. For example, young adults living in a community residence should be allowed privacy, use of the telephone, uncensored mail, personal possessions, freedom of movement, and freedom to practice or not to practice their religion. To the extent that an individual can manage the responsibilities involved, he should be able to come and go from his home, have friends visit, have appropriate contact with the opposite sex, and experience the normal role of an adult.

STAFF TRAINING

In many of the residential facilities the staff has continuous day-to-day contact with the residents over long periods; therefore their potential influence is second only to that of the parents. Thus, they must be given every opportunity to acquire understanding of handicapping conditions as well as the changing concepts of mental retardation so that they are better able to provide a helpful and understanding relationship. Whenever and wherever appropriate, specialized courses on children and adults with special needs should be provided, using a variety of professional consultants. During the training stages each staff member should learn to understand the emotional, intellectual, physical, and social needs of retarded persons, focusing first on their general human needs and only second on special needs related to the particular type and degree of their disability.

Since the staff and residents will have frequent contact with health and welfare agencies, the staff should known these agencies' roles within the community, as well as eligibility requirements, procedures, and types of services. Training should also be provided on the rights of retarded persons and on their eligibility for benefits. Qualifying for and receiving health and financial benefits requires many forms, and unless the staff or the resident is aware of this, many of the residents may lose out on their benefits.

One of the more important elements in a successful training program is the trainer. Usually this role includes such professionals as public health nurses, physicians, psychologists, and so forth. Although they can contribute much to an effective training program, the staff also needs exposure to individuals who can recount real life situations. Many of the staff members themselves can relate incidents they have encountered with residents or agencies that can be beneficial learning experiences for others. The staff themselves should participate in organizing training sessions so they are relevant to their needs.

Retarded persons can be very effective trainers. Their perceptions of the world and assessments of the programs available can provide sharp insights into the areas where training is needed and service systems need altering. As an integral part of any training program, retarded persons should participate actively in planning the training content.

The accessibility and time of the staff should determine the location of training courses. Since the staff may not all be able to meet at one time, sessions may be staggered for both evening and day classes. Although the training program could use various locations, they should be under the auspices of an educational program. A feasible location might be an adult night school, where ongoing sessions can meet without interfering with other classes. This is also more economical, since attending a college campus usually entails parking problems and extensive costs.

Summarizing, the following are primary factors in implementing staff training:

(1) Training structured around the goals of the program
(2) Using a range of trainers from various health and welfare systems, community organizations, and other staffs; and the participation of retarded persons in the training program
(3) Participation of the staff in the organization, structure, and content of the training sessions
(4) Training conducted in a setting accessible to all participants with resources for ongoing sessions.

In addition to formal training sessions, the staff members should meet regularly with other staff in informal discussions, where they can speak candidly. As is the case with natural parents, the staff may need an opportunity to get out from under the routine of the facility and sound off about the problems they may be having with residents or agencies. This healthy exercise can vent frustrations and angers; and it can help one staff member learn from another how to handle specific problems.

RECOGNITION

If the staff members are to feel that they are contributing to the lives of retarded persons and if they are to continue within the program, they should receive recognition. Providing training sessions and consultants may partially accomplish this, but that alone does not provide explicit recognition of their status. At the completion of the training sessions, they should receive certificates or degrees which agencies and professional organizations would officially recognize.

The status of residential staff must also be recognized through just payment for their services. If they are expected to commit themselves to this program, they must receive salaries comparable to those of other staff within the care delivery system.

MONITORING

An active service program evolves according to the expressed needs of its clients. A monitoring process is necessary to assess whether the clients' needs are, in fact, met by the program. Individual progress can be monitored through the administration of an individual program plan. It should be designed around the residents' current functioning level and needs, with concrete objectives on which to focus. Such a plan should include short as well as long-range goals, but remain flexible enough to allow for change within the individual's situation.

Any system of monitoring should stipulate a periodic review of the progress of the residents and effectiveness of the program. Such a review should become a systematic part of the program and should be repeated frequently enough to insure that at every stage in development the resident meets the full range of opportunities necessary for continued functioning. Since this is the basis of the program, the retarded person, or his advocate, should participate in both the individual planning and review. He probably knows best what he needs and whether or not the program is meeting these needs.

SUPPORTIVE COMMUNITY ACTION

The planning of a community residential program should include a range of community leaders, especially those who can can and will exert genuine effort to achieve the program goals. Official links should be established with community agencies which relate to the program. For example, the local chapter of the National Association of Real Estate Boards could help plan and locate a residence or other facility. The local ARC may know of pockets of resistance within the community that may need reassurance about the intent of the program. Opportunities should be sought out to speak with resisting groups and to present the entire picture of the residential program and how the community as a whole can benefit. A campaign should be outlined consisting of the elements necessary to educate the public in this regard. Active involvement of community persons as volunteers, visitors, and advocates can become an effective antidote to many of the problems that will be faced in implementing a program.

PART 4

SERVICES AND COMMUNITIES

CHAPTER IX

A SYSTEM OF SERVICES

by Sheldon R. Gelman

From the discussion in the preceding chapters it should be clear that the diverse needs of mentally retarded citizens approximate the varied needs of others in society. Rich or poor, mentally retarded or non-retarded, urbanite or resident of a rural area, we all strive to fulfill our common yet distinctive needs. The ease with which one accomplishes this depends on a variety of resources (i.e., family, schools, community, human service agencies) designed by society to assist individuals in developing their potential as human beings. A person must have access to a continuum of care which permits . . . . "fluidity of movement of the individual from one type of service to another while maintaining a sharp focus on his unique requirements . . . "[1]

The existing or expanding framework of generic services should provide for the majority of needs expressed by mentally retarded individuals. This does not imply the immediate dissolution of specialized services or a marked expansion of generic agencies, but rather a commitment to include in generic services those previously denied entry. A generic approach to service delivery, based on an accurate assessment of individual needs, helps to reduce the effects of mental retardation on human development and expand the potentials of every human being.

Given the foregoing emphasis, what are the goals of a service delivery system designed to meet the range of needs expressed by mentally retarded persons? The following series of goals can serve as a prototype in identifying the components which will enable a retarded citizen to live and function within his community.[2]

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[1] President's Panel on Mental Retardation, *A Proposed Program for National Action to Combat Mental Retardation.* (Washington, D. C.: Superintendent of Documents, 1962.) pp. 73–74.

[2] Special thanks for assistance in the development of the following section belong to Paul Pearson, M.D., C. Lewis Meyer, Children's Rehabilitation Center, University of Nebraska Medical Center, and Gunnar Dybwad, Professor of Human Development, Heller School, Brandeis University.

GOALS OF THE SERVICE SYSTEM

- *The system should identify and register needs of persons.* The person in need should be the focal point of the system; the initial and continual evaluation and assessment of needs would allow for the appropriate match of the individual to an array of services.
- *The continuum of services should meet these identified needs.* A sufficient range of service components must exist to meet the variety of known needs. Services should be accessible to persons of all ages and all degrees of disability. Services must be comprehensive and appropriate to the needs of individuals. "The various services that should be available in this array must be marshaled in different ways and for different people in accordance with their needs at different times."[3] This may entail developing different forms and modes of service delivery, including outreach, mobile teams, resource centers, and new funding sources.
- *The continuum of services should be provided where possible through generic service systems, to which parents and clients have guaranteed access.* No specialized service should be developed to meet the identified needs of an individual when existing agencies could address such needs. "The 'richer' and more easily available all general services become, the less need for special services for the retarded."[4] The system should stress the importance of the family in planning and decision making. Such an effort will have to view parents as potential resources rather than as obstacles to be overcome.
- *Coordinating mechanisms should exist among agencies and service systems ensuring the goals of the individualized habilitation plan.* All services, generic and specialized, must be linked together to facilitate coordination in line with the specified needs of the individual. An absence of linkages among the various elements in the total system results in a non-system.
- *Service settings must reflect geographic dispersal at the community, area, and regional levels.* The component parts of the service system should be located at levels where clients can obtain them readily. Services should be combined in ways which will ease interdisciplinary approaches to common and

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[3] The President's Panel on Mental Retardation, *A Proposed Program for National Action to Combat Mental Retardation.* (Washington, D. C.: Superintendent of Documents, 1962), p. 75.

[4] *Ibid.*, p. 73.

special needs. Some services should be highly mobile so that distant clients can use them.

- *Service settings should strive to integrate the individual into the mainstream of community life.* The service stystem must strive to create new and more appropriate living patterns for mentally retarded citizens, including participation in the activities of the community appropriate to people of the same age. Such social opportunities pertain to both children and adults.
- *A normal range of options should be available for parents and clients among an array of services. This includes the right to enter and leave the system as the need occurs.* This range of options refers to the continuum of care previously discussed. Individuals may move into or out of the service system as needs arise. Access to and egress from the system must be guaranteed. The system must recognize that some individuals may need combinations of services for a long time, while the majority may "only" require specific services for a relatively short time.
- *Services should be instituted at the appropriate time.* Appropriately timed interventions lead to an improved level of functioning. The effectiveness of late interventions is minimal. Age obviously is a crucial factor in this process. Age is important not only regarding the initiation of a service but also regarding the kind and duration of service.
- *The human and civil rights of all persons should continuously be observed and served, including appropriate habilitation within the least restrictive setting, regardless of the severity or combination of disabilities.* The various recent statements regarding rights and the impact of class action proceedings have opened many new avenues for mentally retarded persons. In Chapter IV, Donald Freedman examines the issues raised by this goal.
- *Record systems should be designed and maintained which facilitate program efficiency and effective service analysis.* Record systems must maintain the continuity of individual program planning, document a client's progress, store reliable information, and assess the program's effectiveness. The records system must guarantee appropriate confidentiality.
- *Program evaluation should be integral to all service systems and reflect the involvement of consumers, system staffs, and the public.* The input and involvement of persons not directly involved in providing service is crucial. A provider of a service is not an impartial and objective evaluator of his own interventions. The agency and the service system of which

it is a part must have built in and ongoing mechanisms for monitoring the quality of its operations.

- *All service systems should be accredited or have plans for achieving accreditation within three years.* This goal will become a reality soon. Mechanisms now exist for all systems, both residential and non-residential, to achieve the standards set forth by the Accreditation Council for Facilities for the Mentally Retarded, Joint Commission on Accreditation of Hospitals.
- *To assure effective implementation and functioning of the service system, qualified specialists should hold positions of leadership in the system.* Without this prerequisite, effectively meeting the diverse needs of mentally retarded individuals becomes an exercise in futility.
- *Mechanisms should be established between Education/Training Programs and the service delivery systems to assure the continuous availability of enough appropriately trained personnel to meet the goals of the service system.* The relationship between education and training facilities (i.e., colleges, universities, University Affiliated Facilities) must be refined to meet the needs of the service systems. Such an arrangement can lead to new methods which may more appropriately meet the needs of mentally retarded persons.
- *Laws should be recodified to facilitate the development of services and facilities to fulfill the goals of the service system.* Legislation has received a great deal of attention in recent years because of the perception that new legislation can answer a long standing problem. The need very clearly is one for good, adequate, and implementable legislation, not legislation which creates additional confusion.
- *Prevention should be an integral component of the service system, and measures should be planned and implemented to reduce the incidence and severity of mental retardation.* This goal, so well articulated by the President's Panel, is a continuing concern. Preventive services must reflect present knowledge and effectively use private and public resources. The potentials that exist through new medical advances (e.g., amniocentesis) and new screening techniques for PKU and sickle cell anemia must be continued. Prevention must be an ongoing part of all components of the service system. In many instances appropriately timed intervention may prevent the need for other services. One man's prevention is another man's cure.
- *An effective means for educating the public and generating public awareness and support should be implemented.* The

need for an adequate and appropriate program of education and awareness must be conducted on several levels (i.e., professionals, the public, and the legislature). This chapter will further elaborate on this goal.

(The above listing of requisite goals is not rank-ordered and may be expanded to reflect the specific characteristics of a community.)

NOW, WHERE TO:

In a chapter like this, one is tempted to set forth an ideal or model service system, with potential universal applicability. However, this is neither practical nor desirable, given the diverse geographic, political, and economic circumstances throughout the country. Nevertheless, the chapter can describe a systematic way of interrelating the functional components of a service delivery system. If one chooses to refer to this exercise as systems design or model-building, he should do so within the context of Kugel's description of a model service delivery system.[5] According to Kugel, a model must consist of a clearly circumscribed, currently functioning entity that can be identified and described. Such a model must contain a range of services. The model must be evolving and have its foundation in a formally defined planning scheme. Its existence is predicated on legislation and is associated with a well-defined geo-political unit.

One may chart the components of a service system to illustrate the range of services which an individual may require to achieve his potential. Such a scheme, presented in the accompanying chart, does not show a totally complete system. It serves rather as a technique to describe various types of services which may be required in an integrated continuum of services. A description of the working parts of existing service systems follows the chart.

HUMAN MANAGEMENT SERVICES

In the inner ring of the chart, a series of nine service headings have been grouped and designated as Human Manage-

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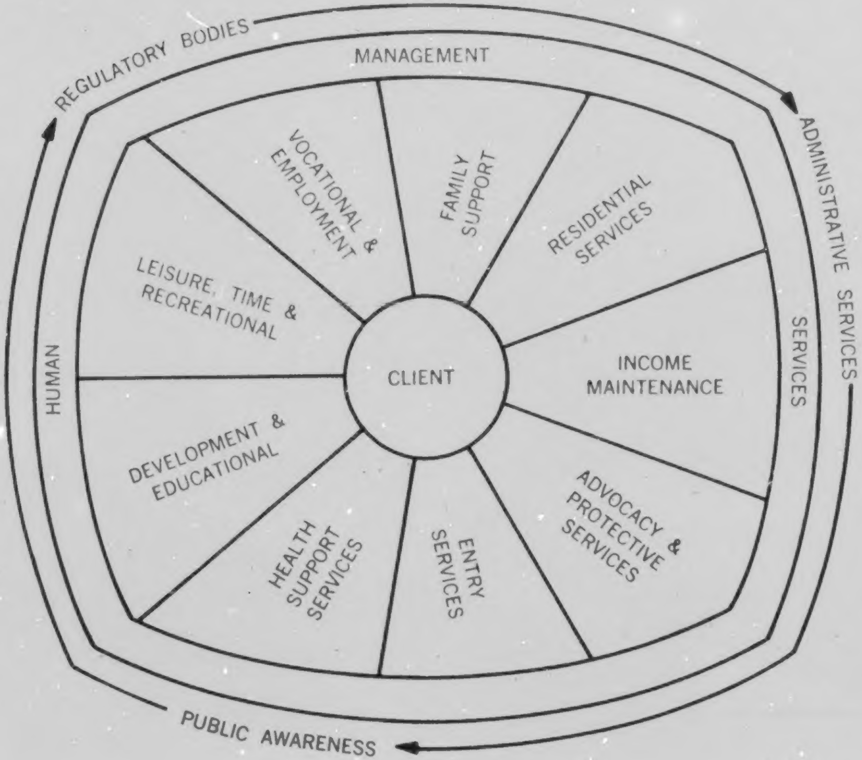
[5] Robert B. Kugel, "Why Innovative Action?" *Changing Patterns in Residential Services for the Mentally Retarded*, ed. Robert B. Kugel and Wold Wolfensberger (Washington, D. C.: Superintendent of Documents, 1969), p. 11.

FUNCTIONAL COMPONENTS OF A SERVICE DELIVERY SYSTEM


REGULATORY BODIES
MANAGEMENT
ADMINISTRATIVE SERVICES
SERVICES
HUMAN
PUBLIC AWARENESS
VOCATIONAL & EMPLOYMENT
FAMILY SUPPORT
RESIDENTIAL SERVICES
LEISURE, TIME & RECREATIONAL
CLIENT
INCOME MAINTENANCE
DEVELOPMENT & EDUCATIONAL
HEALTH SUPPORT SERVICES
ENTRY SERVICES
ADVOCACY & PROTECTIVE SERVICES

ment Services.[6] All of these assess needs or provide direct or indirect services. Although all of these services should be available, given the specific needs and age of the individual, they will be utilized only when required. The service components are not distinct entities but should be integrated and flow together; they are not hard and fast categories.

Entry Services

Entry services include case finding, information and referral, intake, fixed point of entry, and registration. They include the service contract functions as well as the assignment of a case manager or expediter. At the local or area level, agencies designated as Base Service Units, Mental Health/Mental Retardation Centers, or Human Service Centers can best provide these services. Actual location can vary from a storefront to a mobile unit touring the countryside. Available and appropriate services are a prerequisite for prevention. The system, however, requires adequately and appropriately trained staff to carry out these functions.

Health Support Services

Health Support falls into at least two major areas, specific and general services. Specific services include diagnostic and evaluative procedures, necessary medical and surgical interventions, various therapies (i.e., speech, occupational, physical), genetic counseling, and public health nursing. General Services include health screening and preventative activities (e.g., PKU, lead poisoning, sickle cell), health supervision (prenatal and postnatal care, nutritional services), and basic medical research.

Any number of existing private or public resources can provide these services. Private physicians, hospitals and clinics, and Departments of Public Health have the resources, facilities, and expertise to offer a range of needed services in this area. Physicians, medical social workers, public health nurses, or organizations such as Planned Parenthood have or are developing programs on genetic counseling.

Public Health and visiting nurses can provide needed services in health supervision and nutrition and can assist in establishing and carrying through screening programs. Prevention as a goal must remain a prime concern and is essential to all service elements. Support for basic medical research must be continued within hospital and/or university based facilities. Both preventive as well as health support services must move out beyond the existing boundaries of such agencies.

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[6] Gunnar Dybwad, "Action Implications, U.S.A. Today" *Changing Patterns in Residential Services for the Mentally Retarded*, ed. Robert B. Kugel and Wolf Wolfensberger (Washington, D. C.: Superintendent of Documents, 1969), p. 403.

Developmental Educational Services

Developmental and educational services can be discussed as two major categories: Developmental Services for Infants and Toddlers, and School Services. Both broad areas have their own specialized diagnostic and evaluative procedures. Early assessment and intervention in both areas are important preventative tools. Developmental services would provide for intervention and assistance in motor, cognitive, and communication skills as well as in socialization activities. School Services would encompass early childhood education, elementary school programs, secondary school programs including pre-vocational services and the possible use of five-day residential boarding programs, and post high-school programs.

At the local community level, day care, pre-school nursery programs, and Head Start can and do offer developmental programs. Early education programs exist under both the public (Head Start, Home Start) and private (ARC) auspices. Elementary, secondary, and post high-school programs should be provided under the public school system. The entire area of developmental and educational services will expand under the influence of the recent Right of Education court decisions.

Leisure Time and Recreational Activities

Such activities may include craft activities, sports, outings, social clubs, vacations, and adult education. The forcal point for these activities may be the local Department of Parks and Recreation, the Community Center, Scouts, neighborhood groups, service organizations, ARC's, Y-ARC's, and the public schools. Activities such as those developed by such organizations as the Nipon Society of Philadelphia can serve as prototypes.

Vocational and Employment Services

This service component encompasses activities ranging from an ongoing evaluation and assessment of needs and service requirements to follow-up-services. It may include assessment, vocational and technical training, social and vocational counseling, job placement, employment support, follow-up, provisions for sheltered employment, and adult education.

The public school system or vocational training centers can provide these services. The emerging Regional Vocational Training Centers are a valuable resource for those needing specialized training. Linkages must be established between these programs and existing or potential manpower programs, private contractors, unions, and the State employment service. Since mentally retarded individuals spend far more years of their lives as adults than as children in need of academic services, programs and efforts in this area must expand. The successes of the federal government should serve as both a prototype and as an inspiration.[7] Follow-up services are integral to the continuum.

Family Support Services

A wide range of available services and service options lie within this broad category. Services may include Home Start Programs, homemaker services, home sitter, home management, health visitor, dietary assistance, individual and family counseling, respite care, transportation services, crisis intervention, and religious nurture.

Responsibility for coordinating these services should rest with the area center or base service unit, with both public and private agencies actually providing services through a wide range of in-house and outreach programs. The in-home services can be provided on a contract basis with a Homemaker or Home Health Aide Service, Visiting Nurse Association, or public or private Child Welfare Agencies. The center can provide Social Services, including various forms of counseling, or contract for these services with public or private family service agencies. The area center should also coordinate Respite and Crisis services (i.e., 24-hour hot-line) and link them into the residential service component. Transportation services will require coordination with school authorities, regional transportation systems, and private contractors. Religious activities will range from a highly individualized approach observing familial allegiances to the provision of services by ministerial associations.

Income Maintenance Programs[8]

Income maintenance programs include Social Security, Survivors Health Insurance (OASDHI), Social Security Disability Insurance (SSDI), General Assistance (GA) and the Supplemental Security Income Program (SSI). The importance of these programs lies in their potential versatility. Coordination between funding agencies and services dealing with potential recipients is mandatory. These various forms of funding may someday follow the individual and thus facilitate the purchase of necessary services rather than exclude individuals from services because of eligibility requirements or service gaps.

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[7] Ronald W. Conley, *The Economics of Mental Retardation*. (Baltimore: John Hopkins Press, 1973).

[8] Gunnar Dybwad, *Challenges in Mental Retardation* (New York: Columbia University Press, 1964), pp. 85–194; U. S. Department of Health, Education and Welfare, *Mental Retardation Financial Assistance Programs*. (Washington, D. C.: Superintendent of Documents, 1971); National Association of Coordinators of State Programs for the Mentally Retarded, *92nd* Congress: *Federal Legislation Affecting the Mentally Retarded and Other Handicapped Persons* (Arlington, Virginia: National Association of Coordinators of State Programs for the Mentally Retarded, 1973).

Residential Services

Residential services encompass a full range of age-appropriate domiciliary options which may include residence with one's own family, respite homes, individual and group foster homes, community residences, boarding homes, nursing homes, intermediate care facilities, apartments, independent living arrangements, and multipurpose (regional) institutional settings.

Funds for placing individuals in most of these settings are available through reimbursement or existing income maintenance programs. Residential services are one component in the continuum of services which enables an individual to reside in his community.

Advocacy and Protective Services

Protective Services can be either specific or generalized. Specific protective services may include casework services (available from any number of agencies), individual advocacy (i.e., Fellowship Plan, Big Brother/Big Sister, One-to-One, other advocacy programs), Legal Services, Ombudsman, Guardianship, Citizen Advisory Boards, and Periodic Review (periodic review is a joint responsibility of public and private agencies, providers of service, consumers, and interested citizens).[9] Generalized Services include institutional monitoring, advocacy by or for organizations, and the volunteer services of religious or civic groups. Some roles and functions of advocacy are discussed in detail by Robert Perske in Chapter XIII and by Thomas Graf in Chapter XII.

As stated previously, the foregoing service components comprise the Human Management portion of a generic service system. It is *not* an all-inclusive account of possible service options. Services have been grouped in what appears to be a logical order.

REGULATORY SERVICES

Regulatory services entail the various aspects of licensing, zoning, Life Safety Codes (fire-building codes), health and sanitation codes, and wage and hour laws. A state usually mandates and regulates licensing of facilities, personnel, and services. Licensing should guarantee appropriate programs, staffed by certified or approved personnel, which meet the accepted standards in the field. Local ordinances concerning zoning, fire, and health must reflect standards consistent with a normalizing environment. A state must use codes and regulations to *include* mentally retarded individuals in the community, not to *exclude* them or set them apart.

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[9] Sheldon R. Gelman, *Social Policy Implications of Statutory Periodic Review of Residents in State Institutions for the Mentally Retarded.* Unpublished Ph.D. dissertation, The Florence Heller Graduate School for Advanced Studies in Social Welfare, Brandeis University, 1973.

ADMINISTRATIVE SERVICES

This chapter has stressed the importance of planning, coordination, and cooperation. Without them, no continuum of service can exist. Appropriate research and evaluative procedures are crucial for effective planning and coordination. Only skilled personnel and adequate budgetary provisions can generate the range of services required. Citizen advisory boards must share in planning and policy development. Without effective and efficient Administrative Services the Human Management Component of the system lacks the dynamic quality necessary for meeting individual needs.

PUBLIC AWARENESS ACTIVITIES

A public awareness of the scope and content needed for mental retardation cannot and should not be the responsibility of any single existing organization, but should become the joint responsibility of several.

No one agency working in this field is in a position to discharge the full responsibility for this important work, because each is concerned only with special aspects of this program; and broad public awareness, as well as an effective approach to professional groups and other organizations, requires a broader concept and the use of different although related techniques.[10]

The above mandate of the President's Panel explicitly sets out the needed actions in public education and information. Public attitudes resist change and can withstand extraordinary pressure for change on certain issues. In recent years we have made great strides with a variety of media to generate public awareness and acceptance of individuals and groups who in the past have been relegated to a special status. The efforts of the President's Committee on Mental Retardation, the National Association for Retarded Citizens, the American Association on Mental Deficiency, and the Council for Exceptional Children have brought facts about mental retardation to the living room of almost every American home. Public awareness can also be accomplished through agency consultation services to reach both lay and professional attitudes.

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[10] The President's Panel on Mental Retardation, *A Proposed Program for National Action to Combat Mental Retardation.* Washington, D. C.: Superintendent of Documents, 1962.

The message has also traveled other avenues, including the exposure of a variety of dehumanizing situations. These exposés have generated both concern and fear. To avoid resurrecting the stereotypes and prejudices of the past, extreme caution and restraint must be exercised. One case may serve as a guide in this area. Although intended to generate concern and more appropriate habilitative programs for mentally retarded individuals, a series of events in Pennsylvania during 1972-73 may have served to reinforce the perception of these individuals as "deviants." Newspaper and television accounts of conditions in a private licensed facility showed residents "wantering aimlessly in a semi-clad condition around the grounds." A parallel series of newspaper accounts of the same situation as well as conditions in state-operated facilities linked deaths of residents to the activities of other residents. If you add the spectacular disclosure of "wooden cages" as a means of controlling aggressive residents, many cannot avoid a conclusion which emphasizes the "animal-like" qualities of individuals labeled as mentally retarded. The damage of this type of publicity far exceeds the very noticeable gains made through appropriate and constructive media coverage.

ONWARD!

This chapter has no conclusion; it is merely a starting point for what must follow. The mandate and requisites have been set out; the goals and components have been described.

However, let me close this discussion with a few words of caution. A service system without a firm administrative base, without adequate funds for staffing and support systems needed for implementation, without the necessary comprehensive planning and coordination, and without effective linkages to other service systems cannot go far toward improving services to mentally retarded citizens. A well designed and executed service system, geared to the needs of its clientele, sees its service gaps and continually takes the necessary actions to improve the completeness of its services. Effective and appropriately designed monitoring procedures, integral to every service system, can assure this continual upgrading.

> *If then we should discover what is to be done and who is to do it we may slowly come to recognize that we need no oracles—only dedication, wisdom, and above all, common sense.*[11]

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[11] Philip Klein, *From Philanthropy to Social Welfare*, Jossey-Bass, San Francisco, 1971. p. 300.

CHAPTER X

ONE SERVICE SYSTEM AT WORK

by Brian Lensink

THE CHALLENGE

After assuming that services in the community (readily accessible to mentally retarded citizens and their families) are the most reasonable, practical, and humane approach to service delivery, we must confront the specifics of developing a service delivery system. Although administrative designs might offer systems of community services for mentally retarded persons, closely examining one existing system at work might be more helpful. The Eastern Nebraska Community Office of Retardation (ENCOR) has been developing in Nebraska since 1969—when almost no services or programs were available to mentally retarded people in the community. This service system developed through the hard work and vision of a small group of parents and interested professionals, people intent on developing an alternative to institutional care.[1]

Today, six regional offices in Nebraska coordinate community services for mentally retarded citizens across the state. ENCOR, the oldest of the regional programs, has developed most of the service components necessary in a comprehensive system. It is designed to provide a continuum of services to meet the individual needs of mentally retarded citizens—from the mildly to the profoundly retarded, from infancy to old age, and in population densities which range from rural to urban. The services are located in communities throughout the region and integrated into neighborhoods, industrial areas, and recreational areas. Depending on individual needs, the system offers educational, vocational, residential, and family support services. Each program is designed to facilitate the retarded citizen's active movement into education, employment, and independent living in the mainstream of his community.

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[1] See Governor's Citizens' Committee on Mental Retardation, *The report of the Nebraska Citizens' Study Committee on Mental Retardation Vols. 1 and 2*, Lincoln, Nebraska: State Department of Public Institutions, 1968, and *Into the Light*, Lincoln, Nebraska: State Department of Public Institutions, 1968.

See also F. Menolascino, R. L. Clark, and W. Wolfensberger, *The Initiation and Development of a Comprehensive, County-wide System of Services for the Mentally Retarded of Douglas County*, 2nd Ed., Vol. 1, Omaha, Nebraska: Greater Omaha Association for Retarded Children, 1969.

To meet current needs, ENCOR bolsters existing services. As existing services have broadened, especially through generic agencies opening up to retarded citizens, ENCOR has altered its services. It intends only to fill in where existing services are lacking. Since maximum normalization of retarded persons hinges on their greater integration into our society, the system of services offers any service or support which a mentally retarded person might need to live in the community with greatest social-vocational adjustment and personal dignity.

THE IDEOLOGY

The principle of normalization has strongly spurred the current renaissance of community-based service for mentally retarded citizens in our country.[2] Several key ideological principles, encompassed within an overall normalization philosophy, have shaped the way ENCOR services have developed. The major principles include the *developmental model, specialization, continuity, integration,* and *dispersal.* Directly flowing from these important principles are six practices: *consumer participation, human dignity, cost benefit, system flexibility, human scale programs,* and *community support systems.* Figure I illustrates these principles and practices. This chapter will individually discuss the five basic principles and present the six practices later in the context of service descriptions.

The *developmental model* (see Figure II) strongly affects the direction in which a service system develops. Based on the developmental model, programs can modify the rate and direction of client behavioral change. As a retarded citizen grows and develops, the system must allow more independence and less structured program alternative.

The sincere belief that each retarded citizen can learn is demonstrated through programs that prepare a retarded citizen for subsequent steps or goals in his individualized developmental plan. These programs originally aimed at facilitating growth, movement, and progress. The system then accommodates

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[2] See G. Dybwad, Action Implications, U.S.A. Today, in R. Kugel and W. Wolfensberger, (eds.), *Changing Patterns in Residential Services for the Mentally Retarded,* Washington, D.C.: Government Printing Office, 1969, pp. 383–428; see also B. Nirje, The Normalization Principle and Its Human Management Implications, *op. cit.,* pp. 179–195. See also W. Wolfensberger, *Normalization,* Toronto: National Institute on Mental Retardation, 1972.

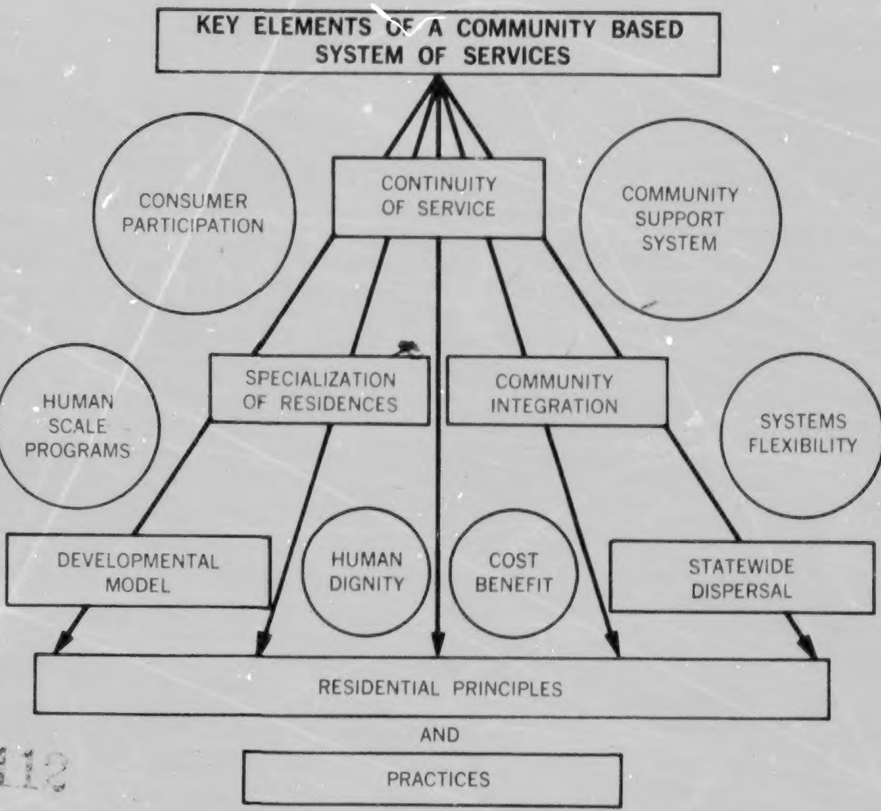
KEY ELEMENTS OF A COMMUNITY BASED SYSTEM OF SERVICES
CONSUMER PARTICIPATION
CONTINUITY OF SERVICE
COMMUNITY SUPPORT SYSTEM
HUMAN SCALE PROGRAMS
SPECIALIZATION OF RESIDENCES
COMMUNITY INTEGRATION
SYSTEMS FLEXIBILITY
DEVELOPMENTAL MODEL
HUMAN DIGNITY
COST BENEFIT
STATEWIDE DISPERSAL
RESIDENTIAL PRINCIPLES
AND
PRACTICES

Figure I

KEY ELEMENTS OF A SERVICE SYSTEM

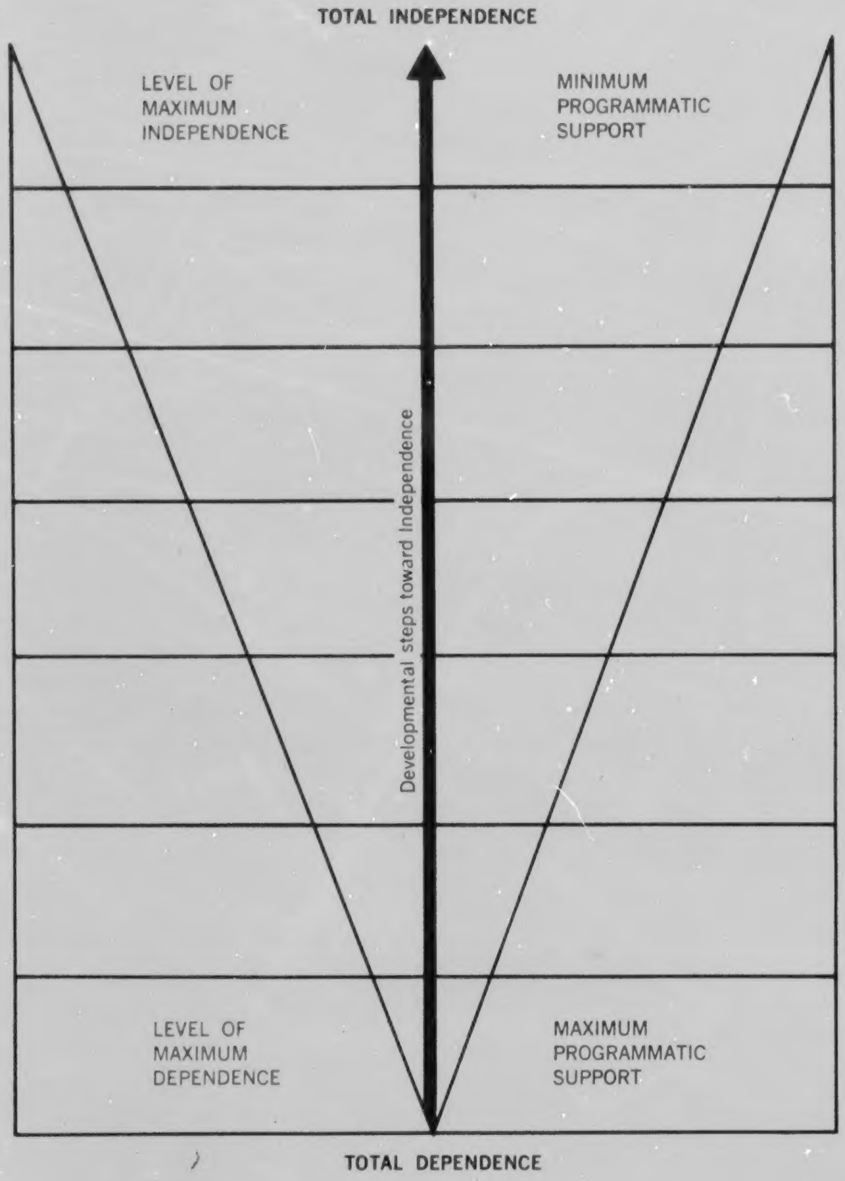
TOTAL INDEPENDENCE
LEVEL OF MAXIMUM INDEPENDENCE
MINIMUM PROGRAMMATIC SUPPORT
Developmental steps toward Independence
LEVEL OF MAXIMUM DEPENDENCE
MAXIMUM PROGRAMMATIC SUPPORT
TOTAL DEPENDENCE

Figure II

DEVELOPMENTAL MODEL

growth and development with program options which take into account the individual's growth through less structure, more integration into the community, and more normalized conditions in which to learn, work, and live.

Small *specialized* facilities and programs enable a system to offer services geared to meet individual needs. For example, one residential setting cannot serve all clients: the moderately retarded person, the medically complex person, and the mildly retarded person who needs little supervision and guidance require different settings. On the contrary, programs can be specialized according to age, degree of disability, or the need for structure or a prosthetic environment. Persons with dissimilar handicaps are not rigidly segregated, but individual needs can, and must be, met within specialized programs.

This principle is particularly important when considering community residential alternatives. Most people in our society sleep, work, and spend leisure time in separate settings—so also should retarded citizens. A residence should provide a home environment: a place to eat, sleep, spend leisure time, relax with friends, entertain, keep one's possessions, or receive telephone calls and mail. Children leave their residences during the day to attend public school or other educational programs. Adults leave their residences to participate in vocational training or to work in the community. Some leisure time activities occur at home, as they do for all of us, but many take place in the community—in theaters, restaurants, community gymnasiums, or parks. The division between home and work or school is just as significant for a mentally retarded person as it is for other citizens in our society.

A *continuity* of programs, a primary objective of a progressive service system, facilitates the growth and development of each mentally retarded person receiving services. Individual development is manifested by a person's movement from a highly structured educational, vocational, or residential environment to a less structured and more normalized setting within the community. A service system can accommodate such developmental movement by providing program options within developmental and residential continua of services. For example, the residential continuum illustrated in Figure III assures that the client who enters the system at the family living residence stage of development has available to him the next step of an adult training residence as well as several future steps. The developmental continuum illustrated in Figure IV assures the same service availability in developmental and vocational programs. This comprehensive system is continually evolving

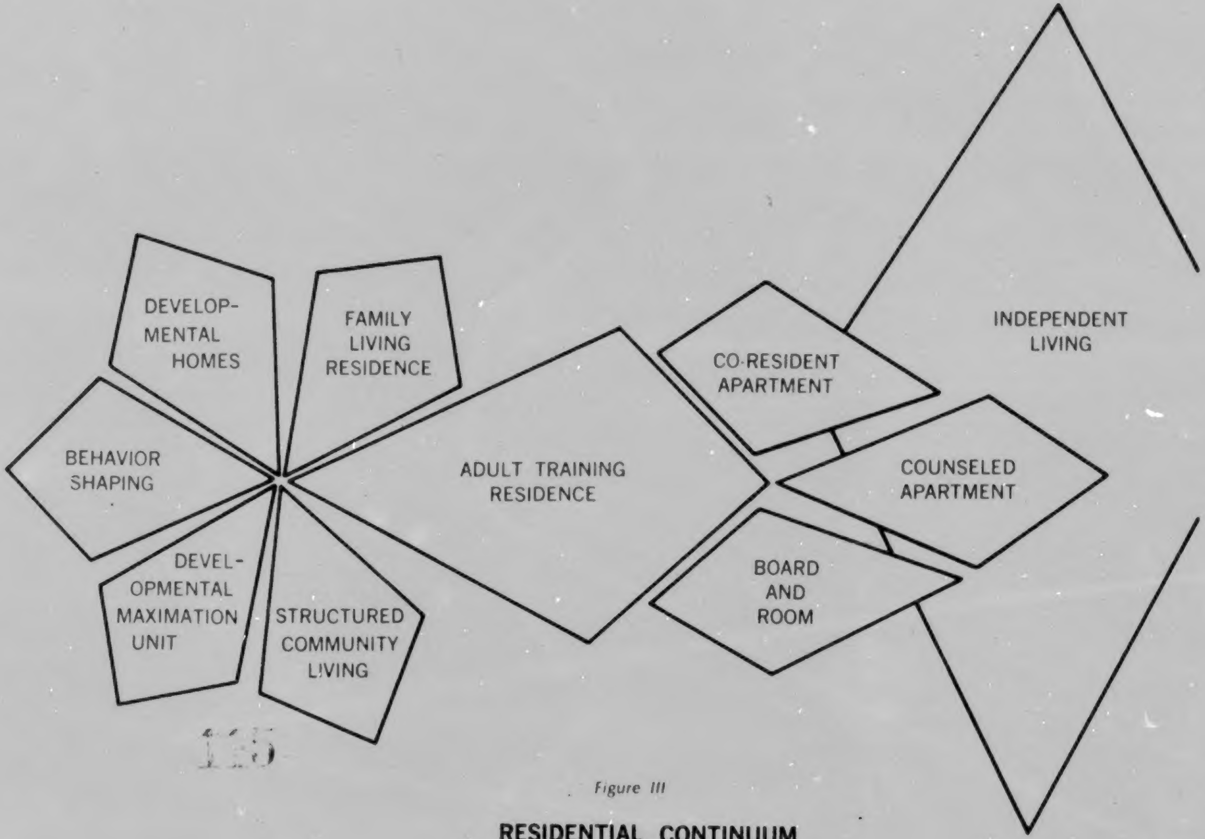
DEVELOP-
MENTAL
HOMES
FAMILY
LIVING
RESIDENCE
BEHAVIOR
SHAPING
DEVEL-
OPMENTAL
MAXIMATION
UNIT
STRUCTURED
COMMUNITY
LIVING
ADULT TRAINING
RESIDENCE
CO-RESIDENT
APARTMENT
COUNSELED
APARTMENT
BOARD
AND
ROOM
INDEPENDENT
LIVING

Figure III

RESIDENTIAL CONTINUUM

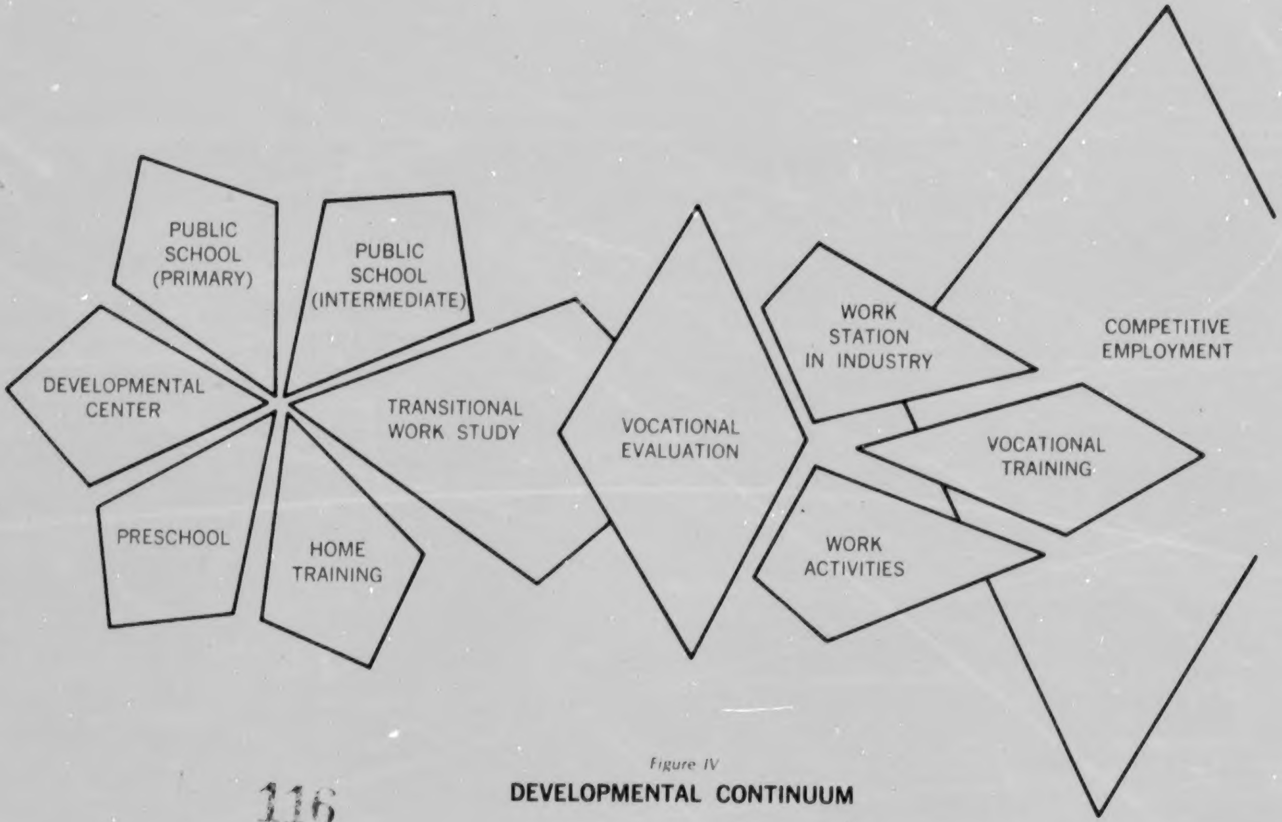
PUBLIC SCHOOL (PRIMARY)
PUBLIC SCHOOL (INTERMEDIATE)
DEVELOPMENTAL CENTER
TRANSITIONAL WORK STUDY
PRESCHOOL
HOME TRAINING
VOCATIONAL EVALUATION
WORK STATION IN INDUSTRY
VOCATIONAL TRAINING
WORK ACTIVITIES
COMPETITIVE EMPLOYMENT

Figure IV

DEVELOPMENTAL CONTINUUM

so that services will never be denied because the system cannot provide the program or support necessary for continued development. These efforts toward continuity of service permit retarded citizens, parents, and staff to see what is ahead of them as they work continuously on their developmental program.

Integration of retarded people into the mainstream of society affords them the same rights and opportunities the rest of society enjoys. A service system can facilitate physical integration by constructing typical housing in popular neighborhoods; by locating vocational training centers in industrial or commercial areas; by securing educational services in ways typical for the community; and by insuring that community resources (i.e., recreational, social, religious, and medical) are available and accessible. Any opportunities for interaction between retarded and non-retarded citizens in the community should deepen social integration. Seeking education for children in the same building or classrooms used by other children, securing work training for retarded adults with other workers in the community, and finding a residence with a real family—all these can greatly facilitate social integration. For true physical and social integration, the community as well as the retarded citizen learn to live together.

Programs must be carefully *dispersed* across a state, across a region, within a city and even within a neighborhood. When a new program or facility is being planned, the planners must consider its location. Because many facilities could present a neighborhood with more retarded citizens than it might be willing or able to absorb, two or three residences should not be established in the same neighborhood. Of course, a program must be readily accessible to clients and reasonably convenient for the staff. While dispersing programs, planners must thoroughly examine the accessibility of vocational and developmental programs for those citizens living in the various residential facilities. All administrative and program decision-making must actively consider the preceding five principles and give them high priority in planning and developing community-based systems for mentally retarded citizens.

THE STRUCTURE OF THE SYSTEM

In Chapter IX, Sheldon Gelman explicitly presents the goals for services and demonstrates the wide variety needed for a truly comprehensive program which adequately serves all mentally retarded citizens. To meet this challenge while implementing the principles and practices critical to an innovative system, ENCOR developed four divisions for the administrative structure of the service system (see Figure V).

These four divisions represent a comprehensive approach to administering mental retardation services. Flexibility is of prime importance to implementing this system of services. As needs, expertise, location, and cost-benefit considerations change, so will the administrative structure of the system. Interdependence between divisions is important to a workable system. No one division should be able to stand on its own without support and assistance from another division within the system. Only this important concept will allow a true "systems approach" to the problem of mental retardation. Repeatedly one notes, in the same community, a series of independent vocational programs, day-care programs, family counseling services, recreation programs, and transportation systems. None of these individual entities, either in a singular approach or in partial combinations with other components, can serve retarded citizens comprehensively. Planning for each component to depend on the other components within the system assures comprehensive and coordinated services. Flexibility also comes into play concerning decisions about what services the system will deliver. As generic community services develop, the system must be flexible enough to let go of its efforts; correspondingly, as new needs are identified, the system must be able to move into those areas.

In the following detailed description of service divisions, it must be remembered that programs and services are directly provided only when existing generic agencies cannot or will not include mentally retarded citizens in their programs and only for as long as it takes these other agencies to meet their legal or moral responsibilities. As counselors identify their clients' service needs, they use as many existing services as possible. Clients and their families might require services in health care, diagnosis and evaluation, recreation, family counseling, family planning, or legal assistance. After identifying a need for generic services, the counselor seeks out the appropriate community agency and assists the family throughout application and follow-through procedures.

Some generic service agencies are routinely used as part of the community's informal network of services for mentally retarded persons. For example, a children's evaluation and rehabilitation service of the University Medical Center diagnoses and evaluates handicapped children under the age of 16 through pediatric, psychiatric, and neurological staff; physical, occupational, and speech therapists; psychologists; social workers;

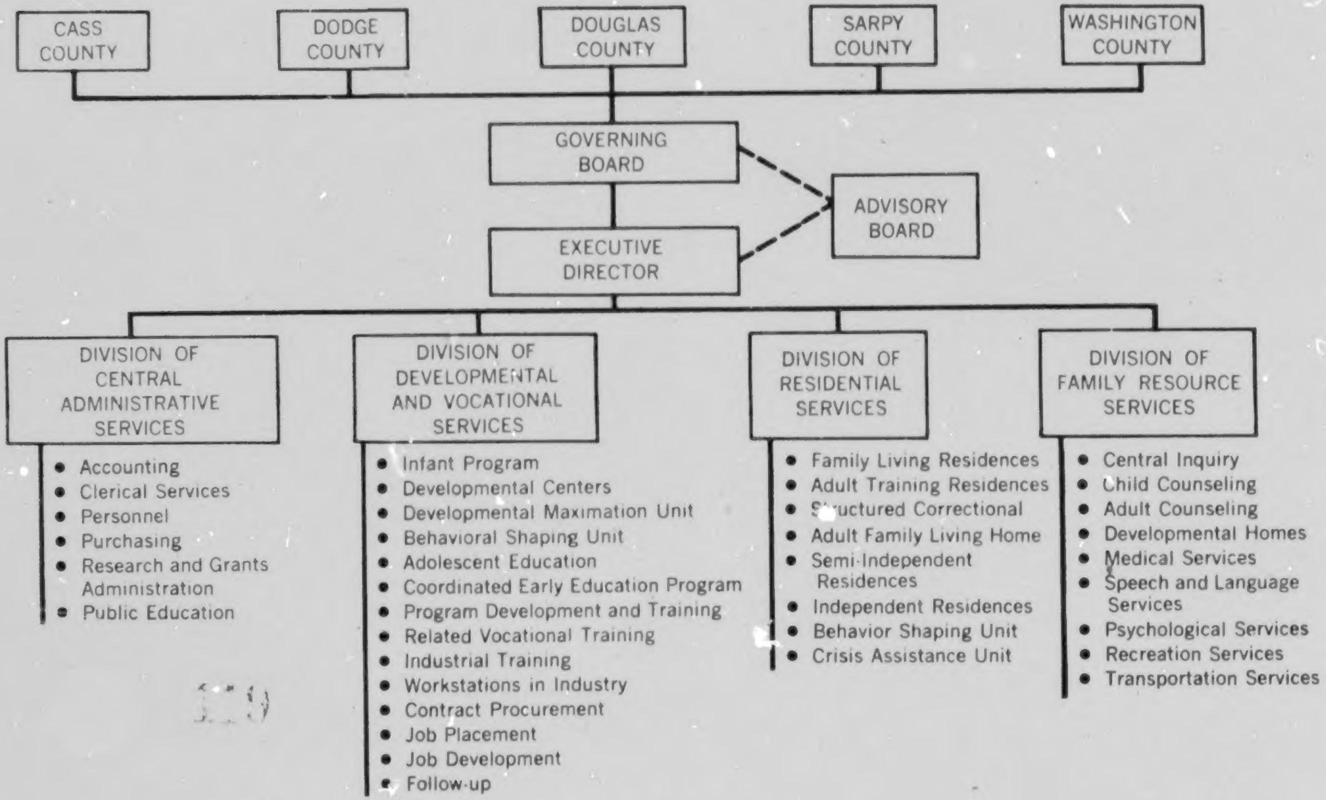
CASS COUNTY
DODGE COUNTY
DOUGLAS COUNTY
SARPY COUNTY
WASHINGTON COUNTY
GOVERNING BOARD
ADVISORY BOARD
EXECUTIVE DIRECTOR
DIVISION OF CENTRAL ADMINISTRATIVE SERVICES
Accounting
Clerical Services
Personnel
Purchasing
Research and Grants Administration
Public Education
DIVISION OF DEVELOPMENTAL AND VOCATIONAL SERVICES
Infant Program
Developmental Centers
Developmental Maximation Unit
Behavioral Shaping Unit
Adolescent Education
Coordinated Early Education Program
Program Development and Training
Related Vocational Training
Industrial Training
Workstations in Industry
Contract Procurement
Job Placement
Job Development
Follow-up
DIVISION OF RESIDENTIAL SERVICES
Family Living Residences
Adult Training Residences
Structured Correctional
Adult Family Living Home
Semi-Independent Residences
Independent Residences
Behavior Shaping Unit
Crisis Assistance Unit
DIVISION OF FAMILY RESOURCE SERVICES
Central Inquiry
Child Counseling
Adult Counseling
Developmental Homes
Medical Services
Speech and Language Services
Psychological Services
Recreation Services
Transportation Services

Figure V

SERVICE COMPONENTS IN PRESENT ENCOR ADMINISTRATIVE STRUCTURE and public health nurses. Most children entering the system go through the diagnostic and evaluation services of this component of the University; consequently, the program avoids duplicating these services.

The ENCOR system strives to stimulate greater community service to mentally retarded citizens through its involvement with a variety of other agencies. Several years ago, for instance, recreation programs for mentally retarded children started in the facilities of a local YMCA. After much discussion with the YMCA, the two systems agreed to a contract prescribing YMCA's greater involvement. It was reimbursed for its expenses and was also provided with training for staff and volunteers, "curriculum" plans for the program, and regular consultation. During the second year of the contract, the YMCA assumed one-half of the expense of this service and is now independently serving mentally retarded children—integrating them into their other recreation programs whenever possible. Thus, through existing programs, local duplication of services has been eliminated while Federal, State, and local funds have been freed for other needed programs. Concomitantly this has promoted the integration of retarded citizens into the mainstream of their community.

Division of Developmental and Vocational Services. Children classified by their school districts as "educable" mentally retarded and "trainable" mentally retarded participate in public school special education. Recent legislation in Nebraska guarantees all children between 5 and 16 years of age a "meaningful education program," placing the responsibility for insuring that all school-age children receive educational services directly on the local school boards. School districts may directly educate these children or contract for educational services for them. The developmental and educational services provided by the mental retardation service system are designed to serve those children not eligible for public school programs.

By October of 1976, the deadline for school districts' mandatory compliance with this law, some of the children presently served in developmental and educational services will be transferred into public school special education classrooms. ENCOR will continue to insist that public schools educate as many children as possible; however, it will continue to present some educational services. ENCOR will serve preschool children and the more severely handicapped children, working to prepare them for entrance into public school or other mainstream educational programs. The local school district will fund this. In addition, ENCOR's support systems for mentally retarded youngsters and their families will remain viable, even if another system should someday assume full responsibility for the direct provision of all educational services.

The *Infant Program* stresses early identification of and intervention with very young retarded children. This new service offers day care in a community day care center to infants (ages 1 month–24 months), focusing on cognitive, language, motor, and social adaptive development. Instruction in developmental stimulation is offered to interested parents at the day care center. For families who do not choose to place their infant in a center, a mobile teacher offers in-home instruction to both parent and child.

The *Development Center* program serves mentally retarded children under 12 who are ineligible for public school programs or other mainstream public (or private) educational programs because of their age or extent of their handicaps. Developmental programs last just long enough to prepare the children for mainstream educational settings. This year-round program operates five days a week on a school-day schedule, with extended hours offered to families needing day care services. The centers, geographically dispersed, serve approximately 25 children each. Whenever possible this program uses existing structures such as churches. The objectives of the Developmental Center programs focus on several general areas of education. Training in daily living skills—such as eating, dressing and undressing, grooming, toilet training, and personal hygiene—is offered to children according to their individual needs. Children may need help in gross and fine motor development, perceptual and sensory discrimination, social skills, cooperative group interactions, and speech and language development. The belief that each child has an individual rate of growth and needs highly personal attention is accompanied by the belief that there is always another step or goal for each student. Progress and success for these students then is the responsibility of the teaching staff. A system of direct and continuous measurement of children's performance allows teachers to maintain an accurate picture of each child's development. Teachers use "precision teaching," a measurement system that O. R. Lindsley and his students at the University of Kansas started developing in 1965.[3] Precision teaching brings accountability to the forefront and allows less subjective analysis of a student's performance.[4]

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[3] O. R. Lindley, Precision teaching in perspective. An interview with Ogden R. Lindsley, *Teaching Exceptional Children*, 3 Arlington, Virginia: Council for Exceptional Children, 1971, pp. 114–119.

[4] See C. Galloway, Precision parents and the development of retarded behavior, in: J. B. Jordan & L. S. Robbins (eds.), *Let's try doing something else kind of thing: Behavioral principles and the exceptional child.* Arlington, Virginia: The Council for Exceptional Children, 1972, pp. 92–109.

The *Coordinated Early Education Program* places preschool children in early education programs in the community. A resource/consulting teacher, trained and employed by the service system, works with four or five young retarded children in an early education center in the community. The retarded children play and engage in learning activities with the other children in the center. To provide specialized support within this normal, active preschool setting, the resource/consulting teacher manages several individualized educational projects with each child (i.e., language development, self-care, motor development).

Two specialized education programs, the *Developmental Maximation Unit* and the *Behavior Shaping Unit*, aim at facilitating children's development so that they might move into one of the less structured, more normalized settings previously mentioned. Severely and profoundly retarded children with multiple handicaps and complex medical problems can be served in a residential/educational program called the *Developmental Maximation Unit*. Most of the children participating in this program have some serious medical problems; therefore, the program seeks to minimize these physical problems so that the children can start learning. A consulting pediatrician extends needed medical care to the children and refers the children to appropriate specialists when necessary. Although the Unit operates in a remodeled wing of a hospital and has emergency access to medical staff and equipment, it does not resemble a medical environment. Draperies, children's furniture, brightly painted walls, carpeting, murals, stuffed animals, and toys of all kinds help make the environment as home-like as possible for these children. Educational priorities of this unit include motor control, the development of chewing, sucking and swallowing skills, the improvement of gross motor skills, and the acquisition of skills for language development. Many of these skills, however, depend on the child's ability to sit upright comfortably. Positioning therapy places a multi-handicapped child in the best functional sitting position with the support of individualized wooden chair inserts. Because this adapted positioning chair stabilizes a child, he can use his upper extremities to their fullest potential. All children tend to develop with these types of imaginative adjuncts to growth.

The *Behavior Shaping Unit* serves severely retarded children whose maladaptive or primitive behaviors prevent them from participating in other programs.[5] Operating according to the principles of applied behavior analysis in educational residential programs, the behavior shaping programs seek to serve intensively the most children in the least time. Substituting appropriate social behaviors for maladaptive behaviors is important for the children's success. Primarily the Behavior Shaping Unit aims to teach the children the self-help skills and appropriate social skills needed for their entry into other developmental programs in the service system or in public schools.

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[5] F. Menolascino, Emotional disturbances in institutional retardates: primitive, atypical and abnormal behaviors, *Mental Retardation*, 10(6), 1972, 3–8.

The *Adolescent Education* program serves children between 13 and 17 who are presently ineligible for public school special education. Again, each child receives an individually tailored educational program, with special emphasis placed upon the development of prevocational skills. Many of these children will enter vocational training at age 17. The Adolescent Education training program allows an age-appropriate grouping and curriculum for teenagers preparing for adulthood.

A young person entering adulthood, regardless of his degree of retardation, leaves the world of the classroom and enters the world of work. Because work is a crucial evaluation criterion in our society, retarded adults must try to develop their work skills and earn the accompanying societal respect and advantages that productive work brings. To accomplish this goal, the system establishes *Vocational Service Centers* (or workshops) with a wide number of evaluation and training services. In vocational evaluation, the client enters the general shop setting. The physical setting is the same for all programs in the workshop and comprises a real work situation rather than a simulated one. During an initial period, the program evaluates a client's potential for ultimate employment in a competitive community setting. At the end of the evaluation period, an individual summation is completed concerning the predicted potential of each trainee. This individual summation directly results in a decision about the client's employment capability. This final summation also outlines the suggested training program for the client and specifies whether he will be placed in the vocational center's training program or in the center's Work Activities Center (long-term development program). The objectives for each trainee —whether in evaluation, work activities, or training—are individualized and designed to bring about greater growth and development, whether their immediately resultant skills lead directly to employment or first to greater proficiency in skills such as money management or performance of a specific work task. Training in vocational service centers takes place through paid subcontract work from local business and industry.

The minimally supervised employment offered through

Work Stations in Industry can also provide vocational services. In these settings, vocational training occurs in an actual community industry or business. Under the supervision of a staff member, a crew of trainees completes subcontract work for the industry or business which houses the work station. Work stations in industry costs little for the service system. The system need not pay rent, purchase equipment, or employ all the supportive staff necessary in a vocational service center. Such an arrangement also profits a company by eliminating the necessity for transporting subcontract and short-term jobs outside its own shop.

The integration of retarded and non-retarded citizens facilitated by the work station in industry is a most important feature of this type of vocational training. The retarded worker learns from other workers, and gains the dignity of membership in the community's work force. As retarded and non-retarded workers clock in, work, drink coffee, eat lunch, and produce together, normalization usually takes place. Work stations have created new possibilities for the more severely handicapped adult. One new work station employee, five years ago determined to be forever in need of a sheltered setting, has competently mastered work tasks with every piece of machinery in the work station and recently completed his first job interview. Another work station is successfully training and placing in competitive employment men and women directly from the "work activities" designation.

A vocational services effort strives for *independent community employment.* Monthly, at least four persons of the 200 adults served in vocational centers and work stations enter competitive employment. A service system must consider creative approaches to the employment of retarded citizens, and must cultivate new employment options. The lack of employment opportunities tends to slow down a system and discourage a staff successful in preparing the retarded citizen for a move. Because a service system must address job development directly and forcefully, ENCOR hired two full-time persons in this area. All nearby businesses must be contacted and regularly re-contacted. The employer must see the retarded citizen as a productive asset and not as an unfortunate needing a goodhearted gesture. If the service system will invest in creative approaches to job development and placement, all retarded citizens can benefit an employer. Individual employment opportunities alone cannot do everything; the system must consider creative efforts such as two-for-one employment. This entails employing two marginally productive citizens to do the job of one—a possibility which allows many retarded citizens to work at their highest ability in a competitive job environment.

DIVISION OF RESIDENTIAL SERVICES

A family should receive the support it needs to keep its mentally retarded child living at home until he reaches an age appropriate for living away from the natural home. When circumstances prevent a child from remaining with his natural family, the child has a right to live in a setting similar to that of other persons his age. An array of residential services are designed to provide this opportunity (see Figure III). These residential possibilities include foster and adoptive placements, small group residences in the community, special purpose residences, and semi-independent living arrangements for adults. The residential settings should resemble other homes in the community. For example, a *Developmental Home* offers a long-term family living situation to a child so that he can gain the sense of identity and security vital to realizing his full potential. Family placements intend that a child will remain in his developmental home until he reaches adulthood and is appropriately ready for more independence. A developmental home provides an environment very similiar to that of other children his age in the community. A developmental home can give a mentally retarded child more than a loving family, however, for developmental home parents are trained to extend the developmental center or public school program into the home environment. Coordinated with the school program, the home carries out the child's specific training programs as designated by his teacher.

Children ranging from 3 to 15 years may live in *family living residences* with a houseparent couple. The surrogate family in this residence allows the children to experience family life as other children do, providing them with intimate contact and involvement with a small group of people. This family living experience forms an important base on which to develop skills in community living. A family living residence may be located in a house in the community, in a duplex, or perhaps in a modern apartment complex with ready access to the community. During the day, children attend Developmental Centers or public school programs. After school, they may play with children in the residence or in the neighborhood. A team effort gets the table set for the evening. Dinner is a time for friendly family interaction around the table, but also provides an opportunity for helping children develop their self-feeding skills and, of course, their table manners. Clearing the table and assisting in washing the dishes may also be a part of the regular operation. Evening schedules vary according to the age of the residents. Teenagers in public school special education classes may have homework to complete after dinner. Younger children may engage in games and special learning projects with staff members. Some evenings the family might watch television, listen to records, or just go for a walk. On the weekends, some children visit their natural families. For the others, activity abounds to keep them busy. In many homes, Saturday morning may be a time for putting the house in order. Children clean their rooms and help with vacuuming, dusting, window washing, and laundry. Even though the staff could quickly and efficiently handle the cleaning themselves, everyone's participation is sought. By helping in these routine procedures, a child can learn about what goes into running a house, learn how to perform some of the tasks involved, and view himself as an essential part of the family unit.

As mentioned earlier, *Special Purpose Residences* such as the Behavior Shaping Unit and the Developmental Maximation Unit provide more specialized developmental/residential alternatives for some children. Children from these units may leave them for their own homes, for a developmental home, or perhaps for a family living residence.

The *structured correctional residence* serves the mentally retarded adolescent whose actions have brought him to the attention of judicial authorities. In dealing with the adolescent offender, who is by no means a hardened criminal, a specialized program in the community is appropriate. A special residential unit, housing eight young persons and perhaps a houseparent couple, may operate under the direction of a person experienced and trained in behavior management. The program in this residence is likely to be highly structured with some degree of limitation imposed upon the freedom of the residents. The structured correctional residence will operate within the developmental continuum of services. The program in this residence will, therefore, be designed to modify the behavior of the residents so that they may eventually participate in less restrictive, more normalized programs in the community.

Several residential options are open to mentally retarded adults. These offer the adult a continuum of residential alternatives which prepare him for and allow him increasing degrees of independence. Programs in *adult training residences* prepare the mentally retarded adult to live someday in more independent situations. By sharing the responsibilities of caring for many of his own needs and of operating the household, the adult resident can learn new skills and develop close relationships with a small group of friends. During the day, the adults living in a residence work in a vocational training program or competitively in the community.

In an *adult family living* home, one to three mentally retarded adults live with a sponsoring family. These adults may be receiving training in a vocational services center or be competitively employed, but not yet ready to live independently and in need of some supervision and assistance. To qualify as a placement site, a family's home must provide easy accessibility to the rest of the community and must resemble other homes in the neighborhood. The house must allow each resident privacy and facilitate comfortable interaction among everyone living there. The attitudes displayed by the family who has opened its home to retarded persons must be constructive, respectful, and appropriate to the age of the mentally retarded persons. The family must believe in the growth potential of the retarded persons and be willing to help them increase their independence and control over their own lives.

Even after a client is living independently, residential staff members and clients who have lived together remain friends. They may sometimes share social activities or birthdays or may spend other special occasions together. Even after a move into an *independent living* situation, a client may still call his counselor when he needs assistance or advice. If the retarded adult experiences no difficulties in living independently, he may break all formal and legal ties to the service system.

To support families of mentally retarded citizens in their endeavor to keep their families intact, the system provides crisis assistance. The first component of this service is a *Crisis Assistance Residence*—a home in the community with houseparents and other staff. Parents can temporarily place their mentally retarded son or daughter in this home setting from which he or she can continue educational or vocational activities. During this short separation, the family might take a vacation or attend to an important situation—perhaps the birth of a new baby, illness of a parent, or an out-of-state wedding. An alternative to the crisis assistance residence is a *Crisis Home* in the community; the agency can contract with families who are willing to have a retarded citizen stay in their home for a short time (from one day to a month). Because only one person is placed in a crisis home at a time, close contact with members of the crisis home family is assured. Both types of crisis residences provide great flexibility.

DIVISION OF FAMILY RESOURCE SERVICES

The Family Resource Services Division administratively groups staff members who provide services to families, clients, and other service system programs. These staff members include counselors, speech therapists, recreational specialists, nurses, psychologists, and psychometrists. Direct service programs do not employ their own teams of specialists and, thus, allow a more cost-efficient use of professional services. Consolidation of these services into one division also allows professionals and paraprofessionals in the same field to share ideas and experiences and to collaborate in innovative program development. All Family Resource service staff members are assigned to family service offices dispersed throughout the region. These staff members use their assigned offices as bases of operation conveniently near the persons they serve.

Centralized Inquiry facilitates entrance into the system of services. A client, a family, or a referring agency in the community has to make only one phone call to find out about entering the system. Basic information about a potential client is taken through Centralized Inquiry and referred to either child counselors or adult counselors serving the geographical areas from which the call originates. *Child and adult counselors* assist clients and their families in seeking out and receiving other appropriate services in the community, facilitate entry into the system, coordinate individual program plans for clients, contract for direct services relating to goals, and provide follow-along services to clients who have left direct service programs. Once a counselor has received the name of a potential client from Centralized Inquiry, he visits the client's home to complete the application procedures. If the system's services are inappropriate for the inquiring citizen, the counselor may assist him in seeking out and receiving other, more appropriate services in the community. If the counselor does feel that services within the system are appropriate, he proceeds in assisting the client in obtaining them.

The counselors coordinate an individual program plan for each client in their family service office area. This individual program plan details the objectives and goals of the developmental services. The retarded citizen, parents, teachers or trainers, the psychologist, recreation consultant, and speech therapist, as well as staff from any other agency serving him, can all be involved in program planning meetings. Long and short-term goals are expressed within a specified time frame and staff members responsible for each objective are identified. Three months later, the same group reviews the client's individual program plan, updating objectives as appropriate. The individualized plan is then reviewed semi-annually for each client. Any direct "counseling" services for clients in developmental, vocational, or residential services are rendered on a contractual basis. Under this system, if a staff member from one of the direct service programs sees the need for special assistance which cannot be easily provided in the direct service program, he sends a request for that assistance to the counseling supervisor for the geographical area in the form of a contract request. The contract describes counseling functions in goal-directed terms signifying that a counselor who engages in a contract becomes responsible for reaching certain objectives with the client. Once a client has graduated from a direct service program, the counselor sees that the client's needs are met. Once a client is successfully employed, is living independently, and does not need his counselor's services, he may terminate formal ties with the agency.

A comprehensive service system must offer *Medical Services*. The system employs two nurses who maintain contact with students in Developmental Centers and clients in residences, acting in a capacity similar to that of school nurses. Although the nurses provide simple medical attention, they refer clients to physicians as necessary. Eighteen physicians in the five county region provide the needed medical care to the retarded citizens living in residences. In this arrangement, since the residence is interpreted as another family unit, the physician simply acts as a family doctor to the mentally retarded persons in the residence. Local psychiatrists provide any necessary psychiatric consultation.

The system also aims at preventing mental retardation. Counselors make referrals to the genetic research and counseling component of the University Medical Center. A cooperative "physician and community education" program has involved both the service system and the Association for Retarded Citizens. Information on mental retardation, its prevention, and local service availability was placed in the offices and waiting rooms of physicians throughout the community. This effort should not only reduce the incidence of mental retardation, but also encourage early childhood intervention, thus preventing more serious future handicaps. Medical students and psychiatric interns receive practical experience in the service system. Through educating future physicians about mental retardation and community service systems, the system will improve early identification and appropriate referrals for educational intervention.

Speech and language specialists serve students in Developmental Centers and trainees in Vocational Service Centers. This staff has outlined a language lattice which shows the ordered development of speech. Through seminars, these professionals have taught other staff persons the skills they need to accelerate language development. The lattice guides all staff members in pinpointing objectives for speech projects.

The *psychological services* staff helps evaluate clients at the time of entrance into the system. This staff also works closely with schools, school boards, school psychologists, and public school teachers in evaluating which developmental center students may realistically enter public school programs. Also working closely with Vocational Service Centers, the staff members aid in program development for pre-vocational trainees. Psychologists are also providing consultative service to residences concerning the individualized projects for clients.

Recreation services are available to any mentally retarded child or adult in the region and do not depend on the individual's enrollment in the service system. The staff strongly encourages community recreation agencies to include mentally retarded citizens in their regular programs. This inclusion helps many children and adults integrate into the leisure time activities of their own neighborhood areas. The direct programming for children provided by the recreation staff stresses physical and social development.

Transportation is available to all retarded citizens who would not otherwise be able to attend their educational or vocational programs. The system expects all adults to use public transportation if at all possible; programs exist for those needing training in how to use this public service. A good transportation system is very important. Children and adults must leave their residences to go to school, workshops, or employment and to maintain a normal rhythm of life. Also, in more rural parts of a region, transportation may be the key to service availability. When looking at transportation for severely retarded multiply handicapped citizens, a system must consider special creative solutions.

The service system provides for the recruiting, screening, placing, and evaluating of *volunteers.* Volunteers only supplement paid staff. These interested citizens can greatly embellish the quality of services as well as help mentally retarded citizens in the community form important friendships.

DIVISION OF CENTRAL ADMINISTRATION SERVICES

The centrally located administrative services are *totally* administrative. No direct service efforts emanate from the Central Administrative Office. Administrative services include personnel, purchasing, accounting, research, grant administration, public education, and centralized secretarial support. Also the Central Administration includes the offices of the Directors of the three divisions within the service system. This centralized location encourages the all-important ongoing communication and planning between divisions. The administrative services benefit all service areas, and each division depends on Central Administration for all administrative support activities.

CONSUMER INVOLVEMENT AND MONITORING

To insure the continued viability and flexibility of the service system, consumer involvement and monitoring activities progress at all levels. Beginning at the very highest administrative level, this effort includes consumers on the Governing Board of the service system. These individuals must be able to express their opinions and effect meaningful changes within the system.

In addition to direct involvement on the Governing Board, the service system should develop an advisory committee representative of consumers and citizens from across the service area. This advisory committee should study all planning and budgeting aspects of the agency and make recommendations directly to the Governing Board and the agency director.

The opportunity for consumers to be continuous agents for change within a service system also implies some direct involvement at the client level. Therefore, each service or program within the system should develop an advisory committee or group which assures the mentally retarded citizen and his parents the chance to make recommendations on individual program considerations. These internal consumer involvement mechanisms will help to insure that the services continue to be those needed by the consumers. However, internal mechanisms alone will insure neither viability nor change within an agency. Some external monitoring forces must be developed.

Parents of the mentally retarded citizens within the service area were responsible for getting the community-based system of services off the ground and consumer involvement in these services continues to play a vital external monitoring role. Through the organization of the local Associations for Retarded Citizens, groups of parents and consumers actively monitor the service system. Human and Legal Rights Task Force Committee visit programs, solicit information about programs from parents and clients, hear grievances, and recommend changes to the staff and ultimately, if necessary, to the Governing Board. In Chapter XIII of this book Mr. Robert Perske discusses various kinds of monitoring systems and their direct relationship to the on-going efforts of a system of community services.

CONCLUSION

In the preceding pages we have closely examined the development and structure of one comprehensive service system for mentally retarded citizens. This system was built on the normalization philosophy. Five major principles—the developmental model, specialization, continuity, integration, and dispersal—underpin this system. The practices derived from these principles—consumer participation, human dignity, cost benefit, systems flexibility, human scale programs, and community support systems—must enter all decision-making considerations of the system. Based on these dynamic considerations, the structure of the service system grew. Four well-designed divisions were implemented with interdependency as a prime consideration. These divisions cooperatively provide a continuum of services for mentally retarded persons. To continue this development and assure that the programs meet the clients' needs, the system must give consumers access to all levels of the service system from Governing Board to individual programs and services. Because this input may not be enough, local Associations for Retarded Citizens must monitor the system to provide an external evluation of it on an on-going basis. These efforts of implementation and management are today's challenges.

In the future, people will probably perceive and accept the mentally retarded citizen as a fellow human being who needs and can benefit from on-going developmental guidance and education within normal community education systems. In fact, a complete network of specialized services providing continuity in a retarded person's life will be integrated into our community services structure. Further, similar systems of service will be integrated into communities across the state and across the country. Mentally retarded citizens and their consumer advocates will demand and obtain equal rights for all retarded citizens and will force states to provide services which accord human dignity. Therefore, large congregate care institutions will be gone forever—replaced by the true integration of retarded citizens into society. Then, all handicapped citizens will enjoy dignity and respect, and our society will be accepting and caring. Under those circumstances no more challenges would apparently exist.

What then would be the major challenge when internal change agentry, efficiency, and a sufficient quantity of services exist within a society? Quality control. And this challenge will rest with the consumer movement which must develop continuously with progressive service systems. Effective consumer monitoring and advocacy will assure a life of dignity and respect for retarded citizens in the years to come.

CHAPTER XI

SERVICE DELIVERY IN RURAL AREAS

by Dennis Popp

The special needs of rural areas seem to have been neglected in the nation's efforts to recognize and cope with the problems of mentally retarded persons. When the federal government arranged in 1964 for "comprehensive" state-wide mental retardation studies throughout the country, only a very few states even mentioned the specific needs existing in rural areas. Yet rural areas still comprise a large part of the nation, from the farm lands in the central United States to the Indian Reservations in the Southwest; from the mountain sections of some eastern states to those of the Northwest.

A report of a community service demonstration project carried on in six sparsely populated counties in Wisconsin cogently summarized the special problems faced by mentally retarded persons in rural areas:

A. In a rural area the understanding and awareness of the retarded's needs and the subsequent impetus to serve him has suffered from the relative lack of exposure to publicity, information, and educational effort.

B. Services for the retarded have not developed in rural areas due to the mechanical problems involved in bringing people together in an area of low population density.

C. In a rural area there is often a lack of facilities such as day care, sheltered workshop, and special classes to serve the retarded.

D. Most rural areas lack diagnostic and treatment centers.

E. Rural areas lack an organizational structure for proper identification, treatment, and referral of the retarded and their families.

F. There is an extreme lack of trained professionals, such as psychologists, social workers, public health nurses and physicians, who can offer service to the retarded or their families.

G. The rural retarded and their families have long been

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unaware of any alternatives to strict custodial care in the home.

H. People in rural areas often have low expectations for their normal child, as well as the retarded, and are unable to see the value of training and education.

I. There is often a stigma attached to family counseling in a rural area, and the fixed point of referral may be located in a clinic or welfare department. Where little stigma is attached, such as the public health nursing service, this office is understaffed in a rural area.

J. Neighbors in a rural area often have less experience with and understanding of the retarded child than their urban counterparts.

K. Parents of the retarded in a rural area are often poor and cannot afford the cost involved in transportation or the child care necessary to attend parent group meetings or take advantage of counseling and diagnostic services for their retarded child.[1]

Increasing resources available, innovations in service delivery methods, and building upon the unique strengths of rural areas may alleviate some of these factors. But many will require new organizational patterns. Many services formerly state-administered or provided centrally will have to be administered on a decentralized basis, often in cooperation with counties. At the same time, other services delivered locally to "normal" persons will have to be supported with special resources from a regional level. A region may be a combination of two adjoining counties, a large segment of the state, or even a territory encompassing areas of several adjoining states. The involvement of a multiplicity of governmental units with different levels of authority and different functions clearly necessitates energetic communication, coordination, and cooperation. But it can be done. Interstate projects for rural mental retardation services, for instance, were developed in Indiana, Kentucky, and Ohio, and between Arizona, Colorado, New Mexico, and Utah.

In actual service delivery the great distances in rural areas require different solutions depending on the nature of service. Individualized services such as guidance and assistance to a mother in managing her severely handicapped infant would suggest that the service be brought to the home. On the other hand, schooling and vocational services require either availability of daily transport or, in cases of unusual distances, a boarding arrangement away from home, preferably for four nights only.

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[1] *A Community Service Demonstration Project for the Mentally Retarded in a Rural Area*, Grant No. MR 5301–A65, April 4, 1966 (mimeo). Central Wisconsin Colony, Madison.

But, despite their small population groupings, diverse political influences, and lack of public and professional leadership, rural areas do possess great strengths, unknown to urban and suburban areas. Rural areas have a cohesive social and cultural pattern that demonstrates concern and acceptance for all "members." A strong local pride is easy to self-generate on behalf of "meeting the needs of our own." Small populations also facilitate a personal knowledge of one another's abilities as well as limitations, leading to formation of more personal relationships.

Typically, however, only one or two persons' energy and guidance lead to the development of services. As long as this energy is present, the service remains. When the energy fades, so does the service. If we are to overcome the current lack of comprehensive rural services and the resulting human suffering, we will need greatly increased efforts to build on local strengths and continued innovation in delivery methods. The following pages describe some positive efforts which build upon local strengths and which use innovative methods.

CASE-FINDING, INFORMATION AND REFERRAL SERVICES

For services to be given, the service provider must identify those needing a service (case-finding); and, on the other hand, the parent-consumer must be able to find out where to turn for assistance (information and referral).

In the absence of the health and welfare agencies typically found in cities, rural areas offer informal informational networks which can help find people needing services. Because through their general knowledge they can assist people to enter the service system, people in these networks are sometimes referred to as "gate keepers." A study[2] made in Vermont (designated by the U.S. Census as the most rural State in the Union) identified mentally retarded individuals in a two-county region and found that such persons as town clerks and postmasters had more such information than physicians and public health nurses. Because of case-finding's being so informal and unconnected to service providers, information and referral has also been informal and undesigned. Many parents have, therefore, been uncertain where to turn, whom to talk to, and how to learn what the future may be like for their child.

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[2] Bruce W. Lagay, "*Mental Retardation in a Rural New England Area: The Use of Gatekeepers to Identify Retarded Persons in the Community.*" Doctoral dissertation, Florence Heller Graduate School for Advanced Studies in Social Welfare, Brandeis University, Waltham, Mass. 1972.

A solution to this problem, first suggested by the President's Panel on Mental Retardation in 1962, is the establishment in a given area of a "fixed point of referral." The Wisconsin rural community service project mentioned earlier approached such a solution by establishing in each of its six counties a fixed point of referral in the person of a specifically assigned staff member of a local agency. In two cases this was the county welfare department, in another two the mental health clinic, in one the public health nursing service, and in the remaining one the sheltered workshop.

These workers spent more than half their time on individual contacts, general evaluations of the presented problem, referrals to the appropriate agency or agencies, and counseling with families so that their initial fears could be alleviated and parents could develop the strength to seek further help. The workers spent the rest of their time on community education, consultation to agencies, and stimulation of new or expanded services. This system succeeded so well in the six-county demonstration area that Wisconsin is now establishing "fixed points of referral" in all the counties.

PREVENTION

In the past, because of the distances, lack of knowledge, lack of manpower, and lack of available media, thinking about prevention within rural areas was difficult. It once seemed administratively impossible to inform every expectant mother of her need for immunization against measles or even to have each one receive prenatal examinations. But today prevention in rural areas is being attacked on a regional and even statewide basis. The University of Nebraska Medical Center,[3] for example, has developed a mass public education program which stresses early and frequent prenatal examinations of mothers whose unborn babies may be at high risk. The Medical Center first aims to reach out with preventive information and to help all mothers of potentially high-risk infants during their prenatal stage. As a secondary prevention strategy, when a newborn child does show definite symptoms of problems associated with mental retardation, the Medical Center has a specially equipped van and a plane to bring in the mother and the infant. This dual strategy of primary prevention and very early intervention has significantly reduced lasting handicapping conditions.

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[3] University of Nebraska Medical Center Report to the President's Committee on Mental Retardation at a meeting in Kansas City on September 21, 1973, Gerard Van Leenen.

Continued mandatory screening and inoculation of children at their entry into public schools will help to reduce the number of handicapped persons in rural areas. New provisions for early screening and medical services under Title XIX of the Social Security Act could greatly help a largely unserved population. This program of medical screening, diagnosis, and treatment of health problems in economically deprived families should prevent many of the problems we now find causing long-term handicapping conditions.

DIAGNOSIS AND EVALUATION

In most rural areas few professional people are available to assess developmental problems and to plan for appropriate treatment and training. Referral for a comprehensive diagnosis, including biological, medical, psychological, psychiatric, educational, social, and other necessary developmental tests may be available at only one or two very distant locations, usually a state university medical center or a state mental retardation training facility. For diagnostic information to be useful to those who seek it—parents and other community agency personnel—the distant diagnostic facility must share it in clear, understandable language. Diagnostic findings must lead to treatment and training that can be carried out by minimally trained or nonspecialized staff. If appropriate goals, objectives, and methods are clearly determined, most treatment and training can be conducted locally. If these measures are taken, only rarely, when specialized and intensive treatment by a highly trained professional is required, will the handicapped individual have to be treated in a distant location.

Sometimes one cannot travel away from home for diagnosis and evaluation. In this case, even the highly specialized services should come to the family. Public and private agencies can purchase specially designed and equipped mobile vans for medical, educational, and social evaluations on a district or regional level. (These mobile facilities can be adapted periodically to meet the needs of various other programs as well.) In particular, mobile vans can be used to train parents and to equip and support professional personnel who come to work in rural areas.[4]

HOME TRAINING SERVICES

In all areas of the country parents with severely retarded infants and young children commonly find themselves facing the task of meeting their child's special needs without helpful continuing guidance. This experience is particularly damaging in rural areas because there is so much less chance of helpful contacts with other parents of handicapped children or with knowledgeable professional workers. Feeding problems, sleeping problems, listlessness, hyperactivity, and lags in motor and speech development greatly concern parents; they need guidance and practical help.

This help may come to the parents through home training specialists employed by a health, mental health, education or welfare agency, through a public health nurse or, especially in rural areas, through a home demonstration agent from the Cooperative Extension Service of the U.S. Department of Agriculture. Ideally, the home training specialists should act as extended arms of local agencies with which they can consult about special problems they encounter during home visits. A good though rare example of this type of service was developed in 1969 in Portage, Wisconsin, originally with federal funds, but now maintained by contributions from 23 school districts.

The Portage Project serves a group of rural counties with numerous small communities in central Wisconsin. On its staff, the Project has ten to twelve specially trained teachers who visit the homes of preschool children with mental and physical impairment, many of them multiply handicapped.

> As children were being identified it was clear that classroom programs could not be provided due to the cost and responsibility of transporting very young handicapped children great distances. In addition, even when several children were identified within a smaller geographical area, i.e., one school district, the variance in chronological ages, functioning levels and handicapping conditions precluded establishing classroom programs. In addition,

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[4] See Jennifer Howse, *Preschool Instruction Mobile Facilities: Description and Analysis*, Southeastern Education Laboratory, 1971. If the mobile unit is used frequently, it should be self-propelled rather than the trailer type. Ordinary small camper vans have been modified for use; truck vans have been used to transport bulky and expensive diagnostic equipment.

classroom programs would severely limit parent involvement due to the geographical and psychological distances between home and school. Thus, a major program decision was made: all instruction would take place in the parent's and child's natural environment—the home.

Thus, the Portage Project is a home teaching program attempting to directly involve parents in the education of their children by teaching parents what to teach, how to teach, what to reinforce, and how to observe and record behavior.[5]

With the aid of a developmental check list the teacher, who visits the home generally once a week for about two hours, helps the parents to see how their child is functioning, determines what they want to teach their child during the next week, records whether the child has progressed, and then has this reviewed by a supervising teacher. The traveling teacher not only gives parents the encouragement they need, but also provides suggestions for new techniques and methods. This project has demonstrated that parents can objectively evaluate their children, teach them, and joyously watch them grow and develop. Where more complicated problems suggest help from other agencies, the teacher can make referrals or at least assist parents with them. When major diagnostic work-ups are required, the teacher, if at all possible, will accompany the parents and the child to the clinic. She is then able to share her observations with the clinic and, in turn to receive a first-hand interpretation of the clinic's observations.

OTHER MEANS OF HOME TRAINING

In some regions, inaccessible or very difficult transportation routes and insufficient personnel prohibit frequent contacts. Still, evaluation and training can be brought into the home. Correspondence courses can be developed (as has been done for many years in New Zealand).[6] The parents receive weekly prescriptive material for use with their handicapped child. Since most homes today have either a radio, a television, or both, retardation services should design specific training programs for radio and television broadcasting at predetermined intervals.

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[5] David E. Shearer and Marsha S. Shearer, *The Portage Project: A Model for Early Childhood Intervention.* Prepared for the conference on Early Intervention for High Risk Infants and Young Children, May 5-8, 1974, Chapel Hill, North Carolina. (Mimeographed.)

[6] R. Winterbourn, "Home Training Through Correspondence—a New Zealand Programme." In: *International Child Welfare Review, 19*:4, 1965.

Television can also be used to train and support parents who are not as isolated. Some public libraries serving rural areas work hard to have available helpful literature for parents of handicapped children and also to present information on how to obtain appropriate films. Telephone, television, radio, and periodicals can also tremendously help the isolated professional and paraprofessional located in rural areas, helping them to keep abreast of current knowledge, philosophies, principles, and techniques.

INFANT DEVELOPMENT CENTERS

Parents can profit greatly from contact with other parents and with professionals associated with the facilities serving their child. Parents in rural areas (where highways are accessible) will drive sixty to ninety miles one way to attend infant developmental programs. They need both the opportunity to relate to other parents of handicapped children and to observe how easily others handle their children. Infant development centers could demonstrate how specialists from different areas can work together to help each child and his parents through explicit steps of development. At these centers the parents also could learn what toys help best with growth and development and how they can build their own toys with simple materials. They should be able to check out toys from the centers just as they would borrow a book from the public library. As the communications media present additional information on growth and development and as more local programs are established, parents can become more secure in raising their handicapped children at home. They no longer have to feel rural isolation.

EDUCATIONAL SERVICES

With the federal courts reemphasizing the right of every child to have an education, new administrative systems and methods are needed to provide educational services in rural areas. Above all, the integration of a severely handicapped child into regular public school buildings is requiring schools to plan for space and equipment which they consider unusual because it is special. These requirements are actually no more unusual than that space and equipment required by other students enrolled in special areas of learning such as chemistry, woodworking, home economics, and so on. A special effort must provide multiply-handicapped children with classroom space without architectural barriers.

Special educational services in rural areas will also call for an expansion of the traditional school bus systems to include specially designed buses to transport multiply-handicapped children in wheelchairs. Since they travel up to sixty miles one way to school, these buses may also carry teachers and training equipment to provide educational and social stimulation to the students.

As school districts become unified in the delivery of special services, there will also be an increase in the recruitment and use of temporary residential programs for five days and four nights. These temporary living arrangements are repeating a historical practice of educational attendance in rural areas; many years ago all of the children in some rural areas were "boarded out" when there were insufficient numbers of schools available for those who wanted to go beyond the eighth grade. A variety of boarding facilities are necessary in rural areas since most "temporary parents" have preferences for the degree of handicapping conditions they can accept in a child. A system must not only find understanding and accepting boarding families but also give them needed back-up services to cope effectively with any special problems the children might present.

ADULT SERVICES

As another major problem, rural areas lack varied work opportunities for individuals or contract work for those adult developmental facilities which use work as the primary training method. For many years simple farming or service job opportunities were the only choices.

More recently, because the agricultural industry became mechanized, opportunities were limited to truck gardening and tasks identified with migrant farming. But the rural environment is now beginning to offer new opportunities to retarded workers.[7] In a southwestern state, for instance, rehabilitation authorities initiated a system which organizes and employs retarded young men in work crews of six and assigns them to tasks in state parks. A similar project has worked well in the park system of a midwestern state. Irrigation, hoeing, and the spraying of citrus and avocado groves have recently been found to offer productive jobs for retarded workers. Groups of retarded workers have been successfully placed with the poultry industry, both on farms and in processing plants. In several of these agricultural occupations both young men and women are employed.

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[7] See *Employment Methods for Severely Physically Disabled.* SRS-DD Grant to United Cerebral Palsy of Kansas, #57-B-603, 1973.

As industries relocate in rural areas and a variety of jobs and subcontracts become available, additional work opportunities for rural mentally retarded young people should materialize. It has been demonstrated that industries can profitably employ handicapped workers, and some are now hiring more multiply-handicapped adults. As industries set aside specially designed space and develop specialized tools and equipment, handicapped persons will integrate into production lines and labor unions. Here again only specialized housing and other ancillary support services can allow this integration to continue successfully.

As industrial development has expanded in rural areas, rural schools in midwest and western states have played a significant role in widening the range of job opportunities for retarded people by introducing work-study programs. When such programs have extended over three years for the individuals involved, substantial vocational benefits have been achieved. Once such a program has gained acceptance and approval, placement opportunities multiply. A cooperative tricounty special education work-study program lists no less than twenty-four different types of work facilities in which students have been trained and employed.

Increasingly, more severely handicapped adults in rural areas can work in work activity centers, sheltered workshops, and adult day-care centers. Because of the difficulties in subcontract procurement some of these centers have been able to provide only "busy" activities. As isolated centers, they are now realizing that they do not have sufficient trained personnel or subcontracts to deliver appropriate treatment and to design specialized training services. Consequently, these centers are entering into contracts with a variety of service agencies at a regional or multicounty level, and these contracts become more and more prevalent as planning becomes more sophisticated at the regional level.[8]

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[8] This trend is well depicted in the philosophy and principles of the new *Standards for Community Agencies Serving Persons with Mental Retardation and Other Developmental Disabilities*. Accreditation Council for Facilities for the Mentally Retarded. Chicago, 1973.

RECREATIONAL SERVICES

While opportunities for adequate schooling for even the more severely retarded child are improving year by year, recreation remains a critical problem, particularly in rural areas. Fortunately, in a number of states the 4-H youth clubs, organized under the Cooperative Extension Service of the U.S. Department of Agriculture, have recognized this problem and come up with a twofold answer. Special 4-H Clubs have been organized to meet the needs of children in specialized classes, and "regular" 4-H Clubs have taken an interest in offering recreational opportunities to retarded children. While some 4-H Youth Members have volunteered as camp staffers, others are helping retarded young people with grooming and other social training. Some of the Extension home demonstration agents also have developed recreation activities such as creative art projects and nature study.

In some areas "Scouting for the Handicapped" programs might be available. Youth groups affiliated with the National Association for Retarded Citizens also have developed recreational programs for young retarded adults, and some of these have been extended to rural areas.

COUNSELING

Counseling services must be available throughout the lifetime of a handicapped person. It is a difficult decision for parents to choose to place their young child in even a temporary boarding home in order to attend school. The emotion experienced by most parents when their child first enters school is doubly experienced by these parents. They feel that only they know the sudden occurrences which can place their child in a dangerous situation and which require immediate, knowledgeable help. However, with expert counseling and understanding, school and community professionals can make this transition less painful for both parents and child. Of equal importance is the availability of counseling to the retarded person in adolescence and adulthood as he leaves the protection of home and school and faces the challenge of life in the community. Only a very few rural areas have a counseling agency, let alone a specialized service geared to handicapped individuals. For the time being, reliance must be placed on volunteers and informed networks.

ETHNIC SERVICES

In some rural areas the majority of the population may represent a single ethnic group. An outstanding example of an ethnic group which initiated services for their handicapped members is the Navajo tribe. Other Indian tribes, including the Mountain Utes, were also involved, and it was an interstate effort as well. The states were Arizona, Colorado, New Mexico, and Utah.

The planning effort included representatives of the following agencies from each state: The Bureau of Indian Affairs, the State Coordinators of Mental Retardation Programs, the Governor's Planning Office, the State Special Education Division, the State Vocational Rehabilitation Services, and the State Public Health Department. Through interagency planning with these tribes and tribe leadership, members of the Navajo tribe were trained to establish and staff a fixed point of referral to provide counseling services, child and adult training services, and special education services. Ethnic groups in most rural areas would need to involve many of the same agency representatives in planning efforts for comprehensive services because overlapping political jurisdictions and several state and federal agencies will provide these services.

CONCLUSION

In the beginning of this chapter we spoke of some of the problems associated with planning and providing services for handicapped citizens in rural areas. We have attempted to point out how various areas throughout the United States are overcoming these problems. Because of the vast geography and the resulting need for specialized transportation and housing, providing comprehensive services in rural areas will always cost more than in urban and suburban areas. But when measured against the human and economic price of unattended problems, these costs should not deter us.

We have made significant strides in the last twenty years as we have proven that parents isolated in rural areas can provide excellent care and training for their handicapped child when given the proper support and guidance. Given the creativity and support of home care services and understandable, clear-cut professional guidance, the rural parents of a handicapped child need not send him away in their quest for services, nor need the child and family languish in need and neglect.

Parents and professionals must continue to demonstrate a creative approach to the problems presented within large rural areas. They must plan for and develop methods and techniques that guarantee that handicapped people receive proper training and treatment at the appropriate time. The pride of people living in rural areas still runs deep, and this pride will enable them to demonstrate a self-determination to meet the needs of their fellow citizens.

But rural areas must not be left alone with their pride as their major strength. To deliver needed community services, rural areas themselves need to receive much greater administrative and financial attention from state and federal governments. In a technological country, rural areas should be able to expect far greater innovation in service delivery methods through greater research and development funds.

CHAPTER XII

OUTREACH IN URBAN AREAS

by G. Thomas Graf

Although authorities do not agree about the exact percentage of retarded persons among us, few would dispute that the problem of mental retardation is more severe in poor populations than in the middle and upper socio-economic levels of our society. The retarded citizen who is poor often lacks the rights and services available to more affluent handicapped persons simply because the poor are unaware of the services available and how to obtain these services. The mentally retarded person in urban poverty requires the same generic services as other retarded persons. While many retarded persons have been deprived of these services, those living in urban poverty have been even more deprived than others.

To meet the needs of mentally retarded citizens in our inner cities, we must understand not only their specific problems but also the political dynamics of change in the American system. The American political system responds to well organized and sophisticated pressure campaigns and influential citizens rather than to the worthiness of a particular cause. The complications and intricacies of the political process seem strange to most people, and especially so to the poor. For centuries mentally retarded people of all socioeconomic levels suffered both the inequalities and dehumanization of our system; only when middle-class parents organized the Association for Retarded Children and pressed for their children's rights did the American system respond. To deny the importance of middle-class involvement in the change process would be unrealistic and certainly misleading to an understanding of the avenues to social change in America.

The parent movement (ARC) historically has been composed of middle and upper-class parents fighting for services and more recently for the rights of their retarded children and adults. In the mid-sixties the national movement began to shift its emphasis from providing services primarily to the children of its membership to obtaining services for *all* retarded citizens. This shift of national association policy has resulted in many states' passing laws mandating various community programs and services for all retarded persons. Many states now have mandatory education acts for exceptional children; others have passed community services acts providing for training centers, vocational centers, group homes, and diagnostic and evaluation services. Concurrently, the national parent movement began to deal more concretely with the particular problems posed by the relationship of poverty to mental retardation. To obtain basic rights for retarded persons, associations have begun to use the courts instead of legislative mandate. Because of this reliance on judicial decisions, middle-class parents could not seek a legal guarantee of the rights of their own alone without also seeking the guarantee for all retarded persons—black, white, rich, or poor.

THE SPECIAL PROBLEMS OF POOR FAMILIES WITH MENTALLY RETARDED MEMBERS

Beyond the political and legal issues, the complexities of urban living and service delivery pose major hurdles for all families, especially the poor. Metropolitan areas with their intricate governmental bodies, service agencies, school districts, boundaries, and overlapping services form an often incomprehensible and impenetrable maze. Simplification of a service-delivery system is seldom a reality in the United States. Consequently, urban living and service delivery problems require knowledgeable advocates for all retarded citizens, especially the poor.

Project STAR was such an advocate. STAR—a recent poverty project conducted by the National Urban League, Family Service Association of America, and the National Association for Retarded Children—concluded that, "There is an overall need to increase the capacity, effectiveness, and efficiency of services to the mentally retarded and their families, but particularly among the poor and minority families. Major problems in the service system that have contributed to this need are:

—gaps in service
—uneven distribution of services throughout the community
—varying quality of services, some excellent and some just meeting minimal standards
—fragmentation of services. Problems encountered here include:

—difficulties for the client in finding the best way to enter the service system

—conflicting and inconsistent eligibility standards, especially for the multiply handicapped

—inadequate mechanisms for comprehensive work-ups and case planning

—inadequate mechanisms for case management continuity for interagency services

—cumbersome mechanisms for assigning costs to the appropriate agencies

—insufficient opportunities for staff development and infusion of new service techniques

—insufficient planning and coordination among agencies with complementary services

—insular attitudes tied to one type of client, disability, or service within agencies (public and private)

—inadequate input from low socioeconomic and minority groups."[1]

A lack of planning and program coordination of the broader service system presents major obstacles to all persons, but especially to the poor. During the past twenty years community services for mentally retarded children have grown rapidly throughout many sections of the United States. As a result of centuries of neglect, programs were too often initiated by a variety of public and private agencies without regard for enough short and long range planning or interagency coordination. In essence, we find an often sporadic array of services in our cities. Although national priority is beginning to shift towards the provision of well-integrated service models, a well-planned and coordinated service delivery system is too often the exception rather than the rule.

The Example of Adult Services. Many community-based service agencies are experiencing the consequences of planning neglect. Specifically, vocational rehabilitation agencies—by virtue of their concern and federal funding for adult services—are just now beginning to feel the impact of effective advocacy and ineffective interagency planning for the mentally retarded adult. Massive program development by one community service agency will sooner or later make an impact on others. Advocacy and public agencies initially demanded services for retarded children, specifically day care and special education. While some enacted mandatory education laws for exceptional children, others received a mandate from the courts that public education is a right of all citizens including mentally retarded ones. The court decisions and legislation mandating education for mentally retarded persons have resulted in identifying and then providing services for thousands of retarded children. We are experiencing a revolution in the development of community-based services for the retarded persons. Because this massive reform in education and other child-oriented services (day care, diagnostic and evaluation, and other treatment services) has caught the traditional adult-oriented service agencies ill prepared, vocational rehabilitation agencies are hearing thousands of special education and day care graduates knocking at their doors for service. This problem will continue to be acute for the inner city adult retarded citizen.

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[1] Long, Earl L., "*A Final Report on Project Star*" (Serving to Advance Rehabilitation), National Urban League, Research and Demonstration Grant Number 15-p-55061/2-03 from Social and Rehabilitation Service, Department of Health, Education and Welfare, Washington, D.C., 1973, pp. 16–17.

If employment and economic progress are major escape routes out of poverty, mentally retarded citizens living in America's inner cities must follow these routes. Why guarantee a person fifteen years of education (3–18) only to deny him the vocational training required to "succeed" in society? Although we must still emphasize creating and opening up employment opportunities for retarded citizens, we should give major priority to developing innovative pre-vocational and vocational training programs. Services for mentally retarded adults have changed little over the past two decades. For the most part we are still witnessing the limited, under-financed, sheltered workshop model of the early fifties.

Traditionally, vocational rehabilitation agencies have maintained a "case closure" mentality. They have given priority to those handicapped people with the potential for fast rehabilitation and case closure. Needless to say, this excluded most mentally retarded people.

Although employment opportunities for retarded persons generally exceed the ability of service agencies to fill them, the need for adult rehabilitation services exceeds the ability of traditional agencies to supply them. While more affluent parents may be able to make their own private short or long term provisions for their mentally retarded adults, this crisis in public provision victimizes the poor. The unemployed adult retarded person in the inner city is at great statistical risk of getting into trouble with the law and entering the criminal justice system. Vocational rehabilitation intervention by the community could save it from more costly and needlessly restrictive offender rehabilitation later on.

In view of these factors, a high national priority must *now* be given to expansion and integration of comprehensive adult services for retarded citizens—especially for those living in inner city poverty pockets.

Unless we follow up with adequate comprehensive adult services, we are wasting all the diagnostic and evaluation clinics, special education classes, day care centers, recreation programs, counseling, and group homes. We should give special priority to vocational training and job placement services for inner city retarded adults.

SPECIFIC OUTREACH STRATEGIES

Even if an ideal coordinated service system for retarded citizens existed in every American community, the poor would still face a very real dilemma. Despite the many available services to retarded persons, low income families know little about these valuable resources and programs. This fact alone produces the need for advocacy outreach services to assist families in obtaining these needed services. Although outreach programs are not the only special need of mentally retarded citizens living in poverty, they are one of the major needs of this group.

The scarcity of literature on advocacy and outreach models reveals the low priority our society places on persons who are both mentally retarded and poor. Aside from several pilot projects administered by the National Association for Retarded Children and a few state and local parent associations, little effort has been expended to reach out to poor families. With the start of Project RESCUE in 1969, the Atlanta Association for Retarded Children was one of the first to demonstrate a concern for mentally retarded members of poor families. Since, as Executive Director of this association, I was involved in developing the outreach project, I will draw heavily on this experience and Project STAR, mentioned above.

Pilot projects RESCUE and STAR represent valuable building blocks for new service models which can be adopted on a broader base throughout the United States.

Administrative Auspices. In developing an outreach program on the local or state level, one must consider two important factors: (a) Which agency can best administer the project? and (b) What are the possible sources of financial support?

A private, independent advocacy organization would be the best sponsor for an outreach program. It would have freedom to act and a pool of strong volunteers.

The sources of financial support should probably be diversified among private and public resources. High costs usually prohibit strictly private support, even though partial support must come from this area. Public funds should be sought from those public agencies least likely to be adversely affected by the advocacy program. Federal or state grants from public agencies removed from direct program operations are the best sources of public funding.

Human Resources. Assuming the appropriate independent agency secures funding from an independent source, we can now consider the operation of a quality service. Experience has shown that a useful outreach program begins with good staff and volunteers, i.e. professional staff, paraprofessional staff, and well-trained volunteer advocates at various levels of professional development. The real success of Atlanta's Project RESCUE has been attributed to its use of indigenous workers as home visitors. According to Patricia S. Powell, Director of RESCUE, "While our paraprofessional home visitors have not had a long formal education in counseling techniques, the home visitors' ability to empathize (enriched by their own similar backgrounds) and to convey their sincere concern and willingness to help has brought about the effective type of counseling needed by families who in the past have been unable to relate to 'ivory tower' therapists."

A model outreach-advocacy staff should also include a social worker, a nurse, and an administrator responsible for supervising and coordinating the program. The professionals train and back up the paraprofessional neighborhood workers or home visitors and also the volunteer advocates. Aside from the standard clerical and office workers, the staff also includes a part-time person skilled in public information techniques. He assists in preparing various types of community education materials and plays a key role in campaigns to recruit volunteer advocates from inner city agencies and neighborhoods.

The second major factor in RESCUE's success was the initial intensive in-service training program for paraprofessional staff. The program included three major phases:

(1) Lectures and discussions concerning mental retardation as a phenomenon: its varieties, causes, degrees, and potential treatments, including special emphasis on behavioral shaping techniques.

(2) Field trips to and discussion of agencies and resources in metropolitan Atlanta which were already providing services to mentally retarded persons. In some cases

the paraprofessional staff could observe and briefly work with mentally retarded persons.

(3) Orientation to other staff members, role allocations within the project, and the importance of openness and cooperation among team members.

Continuous staff training and development progressed throughout the year. Visiting agencies' representatives, lectures, and films are scheduled periodically, and the professional staff members (social worker, nurse) provide continuous education and training in their areas of expertise. The educational process must emphasize practical situations and real problems. As a result RESCUE has experienced a low paraprofessional turnover—one out of seven per year.

This program's success lies in abandoning the traditional selection (academic), training (theoretical), and management (professional over sub-professional) models. It stresses teamwork—working together to help mentally retarded citizens and their families.

Finally, the heart of a good program is the "soldier" in the front line. If the professional staff does an adequate job of selection, provides continuous staff training, and reinforces the paraprofessionals through career advancement, then it has won half the battle.

Program Components. An outreach model should include the following ten components: (1) case finding, (2) referral, (3) parent training, (4) supportive counseling, (5) interagency cooperation, (6) target area-community education, (7) supportive advocates, (8) backup group advocacy support, (9) consumer input, and (10) law enforcement involvement.

(1) *Case Finding.* During the developmental stage of Project RESCUE we found case finding to be our most pressing problem, requiring a high priority. Lee Copple, RESCUE's Project Analyst, discussed these problems in RESCUE 1971 Annual Report:

> "There is no reason to suppose that the projected target population does not exist, but its identification poses unexpected difficulties. As yet, our understanding of these difficulties must of necessity be somewhat tentative and speculative, but we are inclined to think that it is based on one or all of the following elements: as compared to the 'middle class' populations in which case finding for MR services is more often done, our target population is (a) less knowledgeable about the nature of mental retardation, (b) less aware of the difference between a mentally retarded child and their normal siblings or companions,

> (c) less sensitive to community pressures resulting from deviant behavior in children, (d) more inclined to accept the status quo as unchangeable, (e) less alert to community resources for problem solving, (f) more inclined to accept superstitions or guilt explanations of deviancy, (g) more preoccupied with maintaining day-to-day existence, (h) less able intellectually and emotionally to accept help. For these and possibly many other reasons, we do not see anything comparable to the aggressive demand for services for the mentally retarded which has resulted in so much change in national attitudes toward, and provision of services for, the mentally retarded in the last twenty-five years. Rather, we see a picture of apathy, and possibly even secrecy, and this has hampered our case finding."[2]

Clearly, the outreach project must literally *reach out* to the family through its indegenous workers. And when the project does reach out, it may encounter suspicion, rejection, and, in some cases, racial prejudices. Although case finding will never be easy, it should improve once the project becomes better established and known among referring agencies and the target neighborhood themselves.

From the beginning, the project's staff must work closely with potential sources of referrals, for example, Model Cities, OEO, county welfare, and similar agencies. Other potential sources of referral to an outreach agency include vocation rehabilitation, hospitals, public school special education directors, school principals, community recreation directors, churches, juvenile courts, housing authorities, institutions, and health departments. In addition to such agency contacts and liaisons, approaches must be made through neighborhood newspapers, billboards, television, neighborhood organizations, and of course, the residents themselves.

In 1972 RESCUE received a total of one hundred two new referrals from thirty different sources. Success in working with referrals depends on the project's staff going to the retarded person and not waiting for him to come to the office. Once the agency receives referrals, it must determine the problems, needs, and service priorities. The process begins with a professional assessment and family interviews and concludes with a staff conference which sets the priorities and draws up a plan of assistance.

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[2] Copple, Lee B., "*Project RESCUE 1971 Annual Report*," Atlanta Association for Retarded Children, Research and Demonstration Grant Number 5 H30 MRO3125-02 from Social and Rehabilitation Service, Department of HEW, Washington, D.C., 1971, p. 30.

(2) *Referral.* As a second major component, this program must make referrals to appropriate agencies. An outreach-advocacy project intervenes on behalf of a mentally retarded person, his family, and his community; referral is a basic tool of intervention. The home visitor, if he or she is to succeed, must address the needs of the entire family. Intervention may take the course of getting the children to a medical or dental clinic or assisting the parents in finding day care for the children so that the mother can work, thus improving the economic status for the family. In many cases, a home visitor's early intervention with so-called normal siblings can prevent mental retardation from striking again. Assisting the family in good nutrition and health care practices or finding early childhood education experience for the other children can dramatically affect and positively benefit the entire family.

Primarily, both professional and paraprofessional staff should use their knowledge of community resources to help the family and the retarded member receive *all* needed services. Each year the project should review its experiences with all services available to retarded citizens. RESCUE's major 1972 referrals to other agencies are listed below.

PROJECT RESCUE REFERRALS OF CLIENTS

Referrals to	*Number*
Day Care and Training	122
Medical Services	65
Vocational Placement	30
Parent and Client Training	70
Parent Counseling	16
Miscellaneous	60

Earl Long, in the 1973 Final Report of Project STAR states, "Of the known outcomes of STAR referrals, seventy-four percent resulted in a service being delivered to the client."[3] Atlanta's Project RESCUE experienced a similar rate of success with referrals.

In interviews, parents receiving outreach services stated: "The home visitors helped me find services for my child that I didn't know existed"—"they cut red tape"—"I didn't know my young retarded adult could get free medical care from my own doctor from Medicaid"—"I didn't know about Aid to the Disabled"—"they helped me with transportation to the clinic."

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[3] Long, Earl, "*A Final Report on Project Star,*" *op. cit.* inside cover.

Referral implies much more than just telling parents about a service. It often means actually transporting the parents to the agency, helping them with the forms and application procedures, as well as following up the referral. All added up, it means direct intervention.

(3) *Parent Training.* A third major program component and opportunity for intervention, a parent training program, can improve the family's knowledge and skills in coping with the retarded person's problems. Parents need to know about opportunities for their child and about his rights and needs. Home visitors replace abstract, traditional methods with concrete, experimental approaches to teaching. Demonstrating that financial, social, educational, and health services can be obtained has proven to be more effective than words. For example, with Project RESCUE's home visitors, parents of older over-protected retarded individuals went on tours of vocational centers and workshops so that these parents could see first hand other retarded adults succeeding in the outside world.

Sexual needs and behavior are also problem areas for parents. The home visitor can help by teaching a young woman to use prescribed birth control pills correctly or training an adolescent male not to masturbate in public.

In addition to the usual programs in toilet training, feeding, and dressing, other types of successful outreach home training programs include personal hygiene, food preparation, meal planning, child care, budgeting, housekeeping, bus riding, pedestrian safety, and discipline. Assistance in these areas greatly helps to create a better environment for the retarded person and his family.

(4) *Supportive Counseling.* For effective supportive counseling to poor families, home visitors must establish a trusting relationship from the beginning. In 1972 only three families out of one hundred two referrals rejected help from Project RESCUE's home visitors. This success rate can be attributed to the selection of home visitors on the basis of factors other than formal education or experience. Also, an internal staff training program followed by continuous staff education and development activities aids the paraprofessional's successful supportive counseling; therefore, the professional staff must assist paraprofessionals when needed.

(5) *Interagency Cooperation.* Only by developing a close and cooperative working relationship with the staff members and leaders from other agencies can an outreach program meet its broad-based objectives. In 1971 RESCUE listed twenty-three agencies frequently attending case staffings of common "clients."

These agencies included schools, workshops, legal aid, juvenile court, hospitals, institutions, health centers, crippled children services, and housing authorities.

The involvement of various interested agencies in planning for the client reduces duplication of services while exposing the client to the greatest number of possible services. A measure of Project RESCUE's success in interagency cooperation and joint understanding can be found in its low four percent rejection rate for services in 1972. Of two hundred seventy-seven client referrals made in 1972, only eleven were rejected.

(6) *Target Area—Community Education.* The need for changing attitudes and eliminating myths about the mentally retarded person and his needs is just as important in the inner city as in other parts of the community. A good outreach project should include a comprehensive education and public information program aimed at improving the community's understanding of the problem. The program should use newsletters, newspapers, speakers bureaus, radio and television, and all other communication media. Educational campaigns on the effect of lead paint poisoning, rubella, and prenatal care should be parts of the overall public information emphasis. This component of the project can inform the public about the needs of the retarded poor. In addition to these functions, the community education component can help recruit volunteer advocates.

(7) *Supportive Volunteer Advocacy.* The staff of an outreach program is limited in the amount and kind of services it can realistically provide to retarded persons and their families. Although the staff can provide a variety of individual advocacy services, many of their clients' needs must necessarily wait because of staff and program limitations. But a corps of trained volunteer advocates can supplement staff services to retarded persons and their families. Advocates can assist in a variety of areas such as transporting a family to visit their child in an institution, a medical facility, or school; providing homemaker services; picking up surplus food for the family; securing legal aid; or attending a ball game or picnic with retarded youngsters. The possibilities for volunteer advocacy are endless.

The professional project staff should recruit, select, train, and place volunteer advocates. Like the home visitors, volunteer advocates should be selected on the basis of warmth, sensitivity, and concern.

(8) *Backup Group Advocacy Support.* As mentioned, a large social action agency, perhaps a parents' organization,

should administer the outreach project. An individual advocate might find a public agency rejecting a retarded citizen if it were not for the possibility of reciprocal action from the parent organization. In numbers there is truly strength. The community prestige and strength of an association for retarded children provide the individual home visitor with supportive power to meet his client's needs. If the outreach project operates independently or as part of a public agency, it will lack the backup "clout" to meet its advocacy objectives. Under a social action agency with a large membership, the outreach project can channel information into that agency's priorities for legislation, program development, and objectives for social change.

(9) *Consumer Input.* Project RESCUE's parent advisory board aided greatly with information, recommendations, and planning for activities. Members of the poverty population should be encouraged to participate in committees and other activities of the parent organization. They should have a voice in projects that will contribute to improving their own and their children's lives. Outreach consumers can be very effective in a campaign to eliminate lead paint poisoning in their Model Cities community.

In Atlanta, the consumer-based advisory board has undertaken several major projects. It directed a social action campaign at obtaining federal revenue-sharing funds from the city council to replace the categorical grant funding of RESCUE for the first five years. The parents met with individual aldermen to explain the importance of RESCUE services to them and other inner city parents of retarded children. Other direct projects included collection and disbursement of Christmas presents for needy retarded children and their families in the inner city. We have found many articulate and willing consumers who can and want to help shape and improve not only the lives of their own children but also the lives of others.

From a direct service standpoint, the inner city consumer can help vitally in case-finding for the outreach agency. The program's staff must heed consumers if progress is to be made in behalf of the inner city retarded citizen. But we must have more than "paper" advisory committees established to pacify bureaucratic requirements. The consumer must be involved in situations that really count.

(10) *Law Enforcement Involvement.* Within the poverty-stricken inner city a number of mentally retarded persons may be involved in some situation which will require the attention of a police officer. A police officer in the inner city not only acts as a deterrent to crime, but also provides service to the

mentally retarded. To better understand how a police officer can fit within an advocacy outreach model, we will examine these two functions in detail.

The role of the police as a deterrent to crime can cause a problem for the mentally retarded individual if he is suspected of committing a crime. Research has shown that the preferred targets of special police concern are some ethnic and racial minorities, the poor living in urban slums, and young people in general.[4] Thus, a retarded individual may come under suspicion often if he is young, a member of a minority group, or from a low income area. Given this circumstance, one can understand why the policeman can be viewed as a threat by retarded persons and their families. What occurs in the court room can reinforce this feeling. Again, research shows that a young poor person from a minority race will receive a more severe sentence after conviction of a crime than a Caucasian convicted of the same crime.[5]

These circumstances cannot be easily corrected. An advocate/outreach group, however, can take certain steps. First, such a group must meet with the appropriate governmental body which sets police standards for training. This body should be persuaded to introduce a course on mental retardation as part of the regular training program. The proposed curriculum change should clarify the distinction between mental retardation and mental illness. The police trainee or officer needs an adequate understanding of some of the causes of mental retardation. In particular he should know about the relationship between poverty and mental retardation. Most current police training materials fail to do this adequately. When the standards' committee agrees to change the curriculum and increase the number of hours of instruction in mental retardation, those proposing the change should help develop the new materials. In some instances, local Associations for Retarded Children have been invited to instruct police either in the academy or in special workshops or in-service training sessions.

Also, police and trainees must have personal contact with mentally retarded individuals. The trainees need to understand that mentally retarded people often do not look any different, nor would their behavior usually identify them as different. Trainees might visit workshops, training centers, or group homes where they would see the retarded people functioning in a normalized setting. A visit to a hospital for retarded persons would be quite inappropriate since it would not represent them in a community setting. A visit to a local group home would particularly help. The trainee could see that he really will encounter mentally retarded people in his patrol of a neighborhood.

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[4] Bittner, Egon, "*The Functions of the Police in Modern Society,*" National Institute of Mental Health, 1973, p. 10.

[5] Thornberry, Terence, "*Race, Socioeconomic Status and Sentencing in the Juvenile Justice System,*" The Journal of Criminal Law and Criminology 16, 1973, p. 97.

To better the relationship between the community and the police, an advocate group might work closely with the community relations division of the police department. This division provides police officers as speakers to groups of interested and concerned people. The advocate group could suggest that members of the division visit classes, centers, and group homes to discuss law enforcement with retarded citizens themselves. In other words, not only must the police understand mentally retarded people, but meantally retarded persons must learn to understand and appreciate the police.

As another way to help, an advocate group can inform the police about resources to which they can turn when they encounter someone they suspect is retarded. Advocate groups can provide this valuable information as well as the telephone numbers of individuals who will volunteer to be on call in case no professional retardation workers are available.

The next step a concerned group might take involves advocacy in the purest form, individual advocacy. Parents, friends, and relatives are not the only advocates for retarded citizens; policemen can also serve as individual advocates. In many metropolitan areas the Police Athletic League (PAL) shows police interest in personal service. Advocate groups working with the police community relations division or a similar section can develop a program which would give the policeman the opportunity to become the advocate for a retarded individual.

With the emergence of the circumstances described above, the second and equally important role of the police officer as protector can be more fully realized. An officer trained in recognizing and handling mentally retarded persons will be more comfortable in this role when he encounters a situation involving a mentally retarded person. Because only about ten percent of police calls strictly concern law enforcement and the other ninety percent fall into the categories of information gathering, service and order maintenance, the police officer certainly has ample opportunities to respond to people in a non-authoritarian manner.[7] If an advocacy/outreach group establishes a good relationship between the police and the community, the police can function more often as service providers, especially if the advocacy group can establish a mechanism for emergency admittance to a service such as a special group home. This would be a very useful service not only for the police but also for the retarded individual who has to be removed from a potentially dangerous situation. Many states have a uniform alcoholism act which states that an alcoholic cannot be locked up for being intoxicated, but must be treated. An act similar to this would aid a policeman who feels that the best procedure would be the removal of a retarded individual from a potentially dangerous situation. Overnight housing in a community facility—an emergency care unit—would be far better than detention in a jail cell.

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[7] Cull, John, Richard Hardy, *Criminal Rehabilitation Within and Without the Walls*, Charles Thomas, 1973, p. 179.

Although law enforcement is only the first step in the criminal justice process, an advocacy/outreach program can have its greatest impact at this primary entrance to that process. The provisions of alternatives for police handling are preferable to correctional alternatives. A retarded citizen usually need not enter the criminal justice process. In summary, an advocacy group should develop an educational program and offer alternatives to incarceration so that an informed policeman knows where to turn for assistance.

A NATIONAL CALL TO ACTION

We have examined just a few of the problems relating to mental retardation and poverty. We have also seen some specific outreach and advocacy components designed to assist poor families confronted with the problem of mental retardation. As important and helpful as these approaches might be, they still address themselves only to a small element of a much broader concern—eliminating mental retardation caused by poverty and developing comprehensive supportive services for those poor persons already affected by the problem. As mentioned earlier, only a few outreach models are now operating in the United States, and most of those are funded on a short-term demonstration basis.

As a nation, we must attack the total problem of mental retardation and poverty. To make real progress, various advocate agencies for mentally retarded persons and the poor in general must begin to pool their resources and coordinate their efforts.

We know the basic conditions of poverty: segregation, prejudice, racism, poor education, inadequate health care, second-rate housing, inadequate and archaic welfare programs, and an American value system which places a higher priority on technology and objects than on people. As a result of this priority system, a man can walk on the moon and proclaim "one step forward for mankind" while back on earth a child cries out from hunger. In America a retarded child may be denied special education because not enough money is in the school system's budget, and another child denied health care because his family lacks the necessary means to get this help. One step forward for mankind?

Government responds to the "will of the people" as expressed by lobbying power. In the field of health, education, and welfare we have fragmented our efforts. Associations for Retarded Children lobby, Mental Health Associations lobby, National Education Associations lobby, Civil Rights groups lobby; every group does its piece. The returns have been equally fragmented. Yet, the interrelationships of needs are quite apparent. Better schools in ghettos help prevent the perpetuating cycle of poverty and, thus, help reduce mental retardation due to poverty. Yet, the elected officials hear fragmented voices. Because of fragmented efforts in health, education, and welfare, more money goes for space and defense. The implications are clear. The procedure for accomplishing our objectives should be equally clear. We in retardation must begin to work more closely with other social action agencies and coordinate our lobbying and legislative efforts. A federation of individuals and organizations with common and interrelated interests, formed for mutual interests and self-defense without forfeiture of individuality or self-determination, is needed in health, education, and welfare just as it was in the American labor movement. A catalyst must fuse these organizations for their own self-protection. This is also the American way. Through it, we might influence the American priorities in a more humane direction.

If we are to solve the problem of mental retardation and poverty, we need better general education, housing, health care, vocational training, employment opportunities for all citizens. The need for specific outreach and supportive programs for the poor will require federal spending. No one advocate agency can accomplish the mission, but the unified effort of many can begin to bring about positive change.

Our national, state, and local associations for retarded children must reevaluate their own image, their own value system, their own commitment to serving all retarded persons;

black or white, rich or poor. Do we mean what we say? Are we willing to change? Are we willing to get involved? Are parents of retarded children as willing to write letters to congressmen for better health care and education for the poor as they are for specific services for their own child?

Ideally and intellectually we can see the advantages of a lobbying coalition. We have seen it work for other movements and concerns. The real question is not whether it can be done, but rather, are the concerned agencies willing to do it?

SUMMARY

Services for retarded citizens have proliferated during the last decade. Despite this growth a segment of the population remains inadequately served. These citizens reside in America's inner cities; they are the poor who are retarded or who have a retarded family member. This chapter has examined the documented relationship between poverty and mental retardation and the current critical need for adequately planned adult services in inner cities. It has described the necessary basic components for developing an effective outreach service designed to bridge the gap between services and the needs of mentally retarded persons living in poverty. Only a unified commitment of health, education, and welfare advocate agencies will brighten the future of these persons.

PART 5

ACTION AND ADVOCACY

CHAPTER XIII

NEW DIRECTIONS FOR VOLUNTEERS

by Robert Perske

Not long ago volunteers operated almost all community-based services for mentally retarded persons. Today this is changing. Professional community-based services are beginning to appear. That these services are rapidly increasing stands as a tribute to the volunteer efforts of (first) hard-working parents of retarded citizens, (later) professionals who caught their spark of hope and gave their free time, and (still later) volunteer citizens in the community who were turned on to the cause.

And yet, as professional agencies take over the functions of such "parent groups," one wonders what will become of the countless organized volunteer agencies which dot the American scene—volunteer agencies which, with lots of moxie and little money, provided those first services-on-a-shoestring for retarded citizens in the community. The following possibilities can be conjectured:

1. Some volunteer agencies will diminish to less powerful activities, locally. Some may even die out.
2. Others will welcome their new roles and missions as volunteers.

Locally organized volunteers may choose to take the following directions. In doing so, they would tend to come alive in a new, but just as vital, way. They would operate independently as a volunteer organization. Yet, they could develop interdependent partnerships with service agencies for retarded citizens in the community. Since they will develop their own policies and point of view, at other times they may reactively oppose these service agencies.

SOME NEW DIRECTIONS

Public Attitude Change Task Forces: In some towns, volunteer groups are trying to change public attitudes. Now that retarded citizens are coming out of institutions and rubbing elbows on the streets with others, these volunteers have observed new forms of negative attitudes on the part of some. They have observed raw prejudice from a few vocal citizens when small group homes are started on certain blocks. Volunteer task forces have organized to counteract exactly these destructive prejudices toward retarded persons. The following examples show some tasks carried out by such forces:

> One group of volunteer parents of retarded persons organized as couples and visited with all families on a street where the county agency sought to purchase a small group home for four small mentally retarded children from a local institution.
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> Another committee methodically surveys newspapers, TV, and radio for helpful statements about retarded citizens as well as negative ones. They respond with grateful letters to those making positive statements. They respond firmly to those making demeaning ones. For example, when a state-employed physician was quoted in the press as alluding to a small group of multi-handicapped children in a community developmental center as "vegetables," this committee sent letters to him, his superior, and even the Governor, requesting him to correct his vocabulary. Happily, this committee makes nine contacts of gratefulness for every confronting one.
>
> Another committee has recognized prejudice on the part of student bodies and teachers now that more retarded children are attending public and parochial schools. They have organized to visit with school boards and faculty groups to clarify the situation and eradicate myths about retarded persons.

Organized volunteers who work at fostering healthy attitudes toward retarded persons in critical situations may find the surrounding service agencies deeply grateful for their actions in the community.

Agency Monitoring Efforts: Some volunteer task forces will monitor specific community agencies according to an orderly plan. One organization has developed separate task forces for each of the following: community residential services, vocational services, developmental centers, public and parochial school education, and nursing homes where retarded citizens reside.

Agency monitoring by volunteer groups is emerging as a skill with its own body of knowledge. The following functions are currently being refined:

1. Regular visits where check lists or written reports are used objectively and respectfully.
2. Procedures for handling grievances from parents about the agency or vice versa.
3. Developing an ability to respond candidly and firmly when they, as an objective outside group, perceive imperfections in the agency.
4. Pointing out and responding gratefully to areas of excellence.
5. Assisting in the celebrations when a new agency unit opens.
6. Holding press conferences to defend an agency unit that has been unfairly attacked.

Volunteer groups can win a new authority as a helpful monitoring force. As they win respect for their service, some agencies will open themselves and welcome such volunteer action. As a result, the agency will undoubtedly be a better one.

Pilot Parents: Some volunteer groups know of certain parents who have successfully worked their own retarded child into their family system. They are singled out, recruited, and trained as Pilot Parents* who are assigned to parents of newly-identified retarded children. The ones who have "been there" help the others to feel they can make it too. Pilot Parents are not counselors, caseworkers, or therapists. They use a powerful development force, "peer group education." They compare notes, discuss common problems, socialize together, and generally help each other achieve healthy development in the human situation which they share. They help parents find the appropriate community agencies for their child.

Actually, Pilot Parents' activities are not new. This sort of activity has been carried on for years. Recognizing this as a valuable service, volunteer groups have organized it into a coordinated effort. As these volunteers are recognized for the service they can render, agencies and professionals tend to make referrals to such organized volunteer groups.

Citizen Advocates: Now that more retarded citizens are struggling to grow, develop, and make it in the community, citizen advocacy programs are emerging as a helpful aid. After careful screening, Citizen Advocate candidates undergo an intensive training program in learning about mentally retarded persons, their human rights, and human needs. If they successfully complete the course, they are each helped to develop an advocate/protegé relationship with a mentally retarded person to whom they are assigned. They undergo a continuing period of supervision.

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* In this case I have called them "Pilot Parents." Actually such groups have many names, e.g., "Resource Parents," "Empathy Bureau," "Parent to Parent," etc.

Some voluntary organizations work to inspire ordinary citizens from the community to develop a regular one-to-one relationship so well defined that one can even choose the exact level of relationship: ranging from regularly visiting as a trusting friend, to foster parent, adoptive parent, guardian, or conservator.

Creative Programs to Find Quality Guardianships in the Community: Some voluntary organizations are considering finding qualified citizens who will take on guardianship and conservator responsibilities. Because this avenue is new, little can be said about it yet. However, some organized volunteers appear to be coming up with guardianship models of higher quality and increased responsibility.

Youth Relationships: Some voluntary agencies are now developing organized youth relationships. Some center around community-based facilities; others are organized in high schools, churches, and colleges. Some organize as service clubs. The most successful tend to be small groupings of youth in which one-half of the membership is mentally retarded. Some voluntary agencies seek to develop small groups throughout the city and tie them together through a single board of steering committee.

Government and Legislative Action Forces: In the past organized volunteer agencies have excelled at lobbying, testifying at hearings, personally contacting legislators and government officials, holding community forums, letter writing, and participating in telephone and telegraph campaigns. This will continue. In some instances, organized volunteers may choose to team with community-based professionals to form a creative force for healthy government and legislative change. At other times, if social and legislative change is to be accomplished, they may choose to oppose certain community agency policies.

New legislative action may spur more parents of retarded citizens and more volunteer citizens to speak for themselves. Less and less will local voluntary agencies have professionals speak for them. In one voluntary agency, the executive director refuses any longer to lobby or testify; he trains the volunteers to do it themselves. If professional expertise is needed, it is recruited from the community-based agency. Watching volunteers and professionals stand and testify side by side is exciting.

Action Groups in Low Economic Sectors: Most voluntary agencies had their beginnings in the middle class. Now, some have become aware of retardation problems in low-income areas.

At the same time, they have discovered a creative force of people within low-income areas who are anxious to join the cause. As they join and participate in missions for the retarded, the voluntary agency takes on an added healthy quality. Citizens from low-income sectors have much to contribute to the general cause as well as to their own community.

Often organizations must adjust or waive membership dues in a dignified way. In one organization volunteer members are invited to "sponsor" an active member from the low-economic sector of the city by paying the price of that person's membership. Another group assists low-income persons with bus, cab, or auto transportation to places where they can do valuable work. Babysitting may be needed, as well.

One group has assisted persons from low-income sectors to organize campaigns to fight rubella and lead-paint poisoning. It assisted them in their struggles to obtain community-based services in their area (e.g., vocational training centers, counseling centers, public school education, and child development centers). Also, the group computes the number of useful volunteer hours given to the cause, which to this day is increasing. Now, members from low-income sectors serve on the board of directors and on many all-city task forces.

Human and Legal Rights Task Forces: As voluntary agencies work in partnership with community-based services to insure a richer life for retarded citizens, they perceive one painful thing. They see the many human and legal rights that have heretofore been denied to persons labeled "mentally retarded."

Among these are the rights to education, to treatment, to free choice, to risk-taking, to healthy sexual development, to a life as normal as possible, to community living, to the least amount of restriction possible, and to developing one's highest potential.

Voluntary agencies can develop task forces to face both the general instances of denied rights and the individual critical human situations where the joy of living and growing is being squeezed out of a retarded citizen's life because basic human and legal rights are lacking.

Voluntary associations have already confronted larger statewide and communitywide problems even to the point of going to court. Volunteer task forces will apparently now organize to solve individual problems also.

Because of vested interests, community-based agencies are sometimes unable to become involved in such human and legal rights struggles. But the voluntary agency, free of political and governmental ties, can be objective and powerfully influential in such struggles.

Program Innovation Task Forces: In a good partnership between a voluntary agency and a community-based service, volunteers can plan and develop innovative programs which eventually will be "spun off" to the direct service agency.

In one low-income area, a committee of mothers wanted to extend the special education or developmental experience into homes. So, with professional advice, they drew up a grant request for an educational toy library. The government agency approved the grant in the amount of toys and equipment. For more than a year, volunteers developed and staffed the toy library. Then, when it was operating, the toy library was turned over by predetermined plan to a community service agency.

A pilot parent group felt a strong need for current books and information on mental retardation which would help in their relationship with "piloted parents." With technical assistance, the volunteers applied for grant money to develop a book lending library. The grant was approved in the amount of the books needed. The volunteers developed a central library area and many satellite library areas throughout the city in the community-based services and schools. Soon this library will be spun off as well.

Such program innovations again illustrate how volunteer service and direct service agencies can dream, plan, develop, and work together according to a common schedule.

The Power of Ad Hoc Task Forces: Any alert voluntary agency soon learns that ad hoc task forces assigned to a specific situation can have a unique creative power as well as a healthy effect on morale. An ad hoc committee can meet and plan and carry out a task; then evaluate and report on it; and finally disband with every member walking away feeling some sense of worth and accomplishment.

One community-based agency asked its volunteer partners to develop a committee of parents to discuss the situation of two young couples who wanted to get married. They spent three sessions discussing the subject of sex, marriage, and mental retardation. In the last session they developed their "awkward and unfinished" guidelines on the subject. But these guidelines, coupled with those developed by a small group of professionals as well as a small group of retarded citizens, gave everybody some new insights and new directions for the community. Such a volunteer action allowed people to look ahead and plan, even when faced with the most difficult questions.

Examples of other ad hoc committees are:

A committee to study aversive punishment in a specific behavior shaping program.

A committee to focus on a particular piece of legislation concerning the right to education.

A committee of both volunteers and professionals to study medication problems in a small group unit of multihandicapped children.

All Volunteers Are Advocates: The above examples are only a few of many now emerging. But all this work has two aspects.

First, *volunteers do the meaningful work.* If the voluntary agency has paid staff, their job is to recruit, train, inspire, enable, and sustain volunteers in doing meaningful jobs. This kind of work is a far cry from envelope stuffing, stamp licking and general "dog-work."

Second, everything the voluntary agency undertakes tends to be group advocacy, individual advocacy, consumer advocacy, citizen advocacy, youth advocacy, or other types of advocacy. Although a mentally retarded citizen may need many supportive services to make it in the community, he may also need a wide array of volunteer advocates.

SOME HARD FACTS THAT MUST BE FACED

Any voluntary agency that successfully emerges with some new directions must confront certain hard situations. A few of them follow.

No Longer "Parents Alone": In the early days of voluntary organizations for retarded persons, the parents banded together, shared in each others' problems, and started the first community services. For the most part, these parents were very much alone.

But, as they succeeded, professionals volunteered their free time. Then, catching the spirit of this new movement on behalf of retarded persons, other citizens chose to join the cause. Today a successful voluntary organization has parents, professionals, and citizens, locking arms and moving forward together.

Parent Loyalties Will Be Divided: Some parents will continue to be thrilled that new community services are coming to their community. They will be willing to work hard and to advocate for them. Other parents may not be so enthusiastic. Some may feel that their son or daughter has all the service he or she needs and will feel no urge to advocate further. Others will not see community-based services as something their son or daughter should have. Instead, they may tend to see the institution as the only place for their child.

Voluntary Organizations Are Dispensable: Many volunteer groups have worked, thrived, and achieved at certain points in history. Then, when other agencies take over the activity, the volunteers tend to diminish. Voluntary agencies have provided many community services for retarded citizens. Now that others have assumed this responsibility, the voluntary agencies must come alive with another cause and mission or they will eventually be dispensed with. A voluntary organization must be genuinely useful to survive.

Voluntary Agencies Can't Compete with Efficient Comprehensive Community-Based Services: It is quickly becoming impossible for voluntary agencies to do the job of direct service delivery as efficiently as professional agencies with the backing of legislative mandates and government funding. Voluntary agencies must find a new strength and serve as the strong supporters, confronters, and monitors of those services. Furthermore, they must achieve a new cooperative relationship with organized volunteers working for cerebral palsied persons and persons with epilepsy and other developmental disabilities. In a sense, voluntary associations have been hoping for this relationship for many years.

SOME HOPEFUL OPPORTUNITIES

When the problems surrounding change are solved, unusual opportunities seem to arise. The following are a few.

Parents Will Continue as a Vital Force: When parents give birth to a child, they're in for some work. If the child has retardation problems, they'll have some extra work. Those successful in accomplishing the extra work needed to understand, accept, and adjust their child into the family system often find increased growth and development in themselves. Persons like those often become the longtime stabilizing force of a voluntary agency. Since their longtime relationship with their retarded child keeps them involved, they may be more stable. Meanwhile, professionals often shift their loyalties; they may even work for a while in mental retardation and then move to another field.

Parents, Professionals, and Citizens Should Train Together Often: As awkward as it may seem, some of the most creative breakthroughs in our movement resulted from these three types of persons getting together to carry out a critical task. They didn't always speak the same language. But we are learning that these individual differences help groups to be more creative. Organized parents can have an uncanny way of confronting and provoking new thinking in professionals. Likewise, the professional has much to teach parents. The citizen watching such interchanges can offer some remarkable things from his perspective. The voluntary organization can provide the arena for this fertile three-way creative process.

Community-Based Services Can Thrive When in a Strong Partnership with an Efficient Voluntary Agency: The possibilities of a two-way partnership are numerous. Each has a separate well-defined division of labor. The volunteers can advocate government funding for the community agency. The community agency can advocate donated funds for the voluntary agency. Professionals can leave their agencies in the afternoon and work as volunteers in the evenings. Volunteers and professionals can testify at hearings together. These are only a few of many creative opportunities possible.

A Fertile Body of Knowledge about Volunteers is Emerging: Today we are learning much about understanding volunteers and enabling them to do valuable work. An exciting body of knowledge is emerging. One can learn the way to successfully reinforce and gratify achieving volunteers. One can even direct volunteers so that they neither underachieve nor are exhausted. They can be protected and respected as valuable persons, and they needn't be exploited. People will volunteer for a cause that excites them and helps them to make this a better world. The "age of volunteers" is here; if our cause does not capture the interest of people, other causes will. Paid staff persons in volunteer organizations learn to develop creative skills as "inspirers" and "enablers" of others who do the meaningful work. They learn that in a voluntary agency esprit de corps comes when "success is allowed to build on success." When they feel they want to leave, volunteers can be helped to terminate with dignity. One learns how to help volunteers to feel as if they were part of a family-like task force as well as a member of a large mission. In short, volunteer agencies can be alive. They can be exciting. One can develop a deep sense of achievement in them, while doing a lot of good at the same time.

CONCLUSION

One can look back and marvel at spunky local volunteer associations for retarded citizens who with much energy and enthusiasm helped our civilization to make a social somersault. Once, those called "mentally retarded" were expected to live out their lives in institutions; today, society expects that they should live in the community. Community-based services are a growing reality.

But, one wonders what will happen to those many local voluntary organizations which worked so well to bring us this far. What will become of them? What's ahead?

Clearly, in this age of volunteerism, the local volunteer associations can thrive in some new ways. They could develop a wide array of thoroughgoing advocacy programs. They could develop a healthy independent partnership with community-based agencies. Frankly, community-based agencies need their volunteer partners: sometimes the volunteers will collaborate with them; sometimes the volunteers will objectively disagree and confront them. But the agencies need these partners all the time.

CHAPTER XIV

THE POLITICS OF COMMUNITY ACTION

by Thomas P. Holland

ADVOCACY FOR RETARDED PERSONS

To persons labeled as retarded, the allocation of social resources and human services in this country has been limited. Before the 1950s few services were available to them besides residential care in remote institutions. The subsequent rise of the parents' associations provided a framework for organized political pressures at national, state, and local levels for increased services and resources for mentally retarded citizens. The 1960s saw a series of legislative actions which sharply increased the appropriations in this direction; and by the early 1970s, the federal government alone was spending well over a half a billion dollars per year for this group.[1]

In the next decade, one area of human services needing extensive attention is the development of a range of supports or "social utilities" to enable handicapped persons to live in their communities.[2] The conviction has grown that our society can and should provide a basic supportive framework to enable retarded persons to have a life style as near as possible to community norms.[3] Not less than others, retarded persons need the community services that many people draw upon, such as employment referral or counseling, recreational resources, financial guidance, health care, and others. Frequently, however, such services are not readily available to this group for a variety of reasons, which may range from a simple lack of the service to a systematic discrimination in existing services against retarded individuals.

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[1] Robert Segal, *Mental Retardation and Social Action*. Springfield, Ill.: Charles C. Thomas, 1970; Thomas P. Holland, Changing social polices on mental retardation, *The Social Service Review*, 46, No. 2 (June 1972), pp. 251–262.

[2] Alfred J. Kahn, *Investments in People: A Social Work Perspective*. New Brunswick, N.J.: Rutgers University Urban Studies Center, 1963, p. 6.

[3] Bengt Nirje, "The Normalization Principle and Its Human Management Implications," in Robert Kugel and Wolf Wolfensberger (eds.), *Changing Patterns in Residential Services for the Mentally Retarded*, Washington, D.C.: President's Committee on Mental Retardation, 1969, pp. 179–195; Gunnar Dybwad, *Challenges in Mental Retardation*. New York: Columbia University Press, 1964, pp. 83–98.

The effort to develop a normal environment for any minority group must overcome limited access to resources and services. Furthermore, groups which have suffered systematic exclusion may need an even more active effort to mobilize and coordinate the delivery of human services to them. This paper will examine some of the strategies which could mobilize supportive human services in the community on behalf of retarded persons.

Advocates for retarded persons may come from numerous sources: individuals whose families or friends include a retarded person, neighborhood groups or school committees, parents' associations, religious organizations, staff or boards of private or public human service agencies, community or regional planning boards, and elsewhere.

The methods of action available to such advocate groups are varied, but generally involve the *planned exercise of social and political influence* to expand the share of community resources and services available to retarded persons. Such activities begin by specifying the service needs of this population as well as by identifying the community resources available to meet such needs. Next, the methods by which the services may be expanded or oriented toward retarded persons must be analyzed. The advocating group then must measure its capacities and resources for influencing the target services and then match those "levers" against the objectives. Let us examine these basic processes of selecting targets and objectives for change and applying our resources to bring about the desired outcomes.

DOCUMENTATION OF NEEDS AND POTENTIAL SERVICES

To derive accurate plans for social action, an interested group must begin with a careful examination of the situation it seeks to change. Initially it must carefully document the *needs* of its consumer group. The service needs of retarded persons, like those of others, vary in extent, scope and duration. To live in the community, many retarded persons need varying amounts of a range of services: housing, employment, financial planning or assistance, education, recreation, health care, and others.

For example, fewer retarded children would have to leave their families and enter institutional care if they had equal access to such resources as day care and kindergartens, after-school recreational and athletic programs, Boy Scouts and Girl Scouts, not to mention such basics as equal attention and opportunities in public schools.[4] Likewise, far more adult retarded persons could live more normal lives in the community if they had training in the basic components of employment—not only the development of marketable skills, but also such necessary supplementary skills as handling job interviews, getting along with supervisors and fellow employees, getting to and from work, arriving punctually, and so on. Although some retarded persons may need special assistance in financial management, this could be viewed merely as an extension of many persons' use of expert assistance in such complex responsibilities as preparing their tax forms or handling their property transactions.

Basically this initial phase should document the specific needs of retarded persons to enable them to pursue normal lives in the community. With such needs specified, a group of advocates could set the initial broad goals of obtaining the services required to meet these conditions.

Attention is then directed outward across the community to identify the existing services and resources. Following the list of needed services, such questions arise as: which of these services exist for any group in this community; whom do these programs now serve; to what extent are they actually or potentially available to our group; how accessible are they; how effective are they; and finally, what would it take to make them more satisfactory for our needs. (Community Service Directories developed by many "United Way" agencies may be useful beginning inventories of the range of available human services.) While the group might find one or several potential resources for some of its documented needs, the existing services will probably fail to match other needs, indicating gaps in the service resources of the community.

THE ALLOCATION OF SERVICES IN THE COMMUNITY

Some of the existing community services probably devote few of their resources to retarded persons. Such situations do not exist because of chance or some "master plan" and often, as numerous parents have discovered, do not yield to individual appeals for change. Rather, the existing distribution of services

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[4] Gunnar Dybwad, *The Mentally Handicapped Child Under Five.* New York: National Association for Retarded Children, 1969.

—be they housing, finance, recreation, health, or others—results from the policies, values, and numerous political forces which maintain the present situation. Influences to constrain or restrict services further counterbalance influences to extend services. The competing interests of many groups interact to achieve the existing allocation of resources.

For example, a parents' association in one community was presenting a plea to the school board for expansion of pre-school programs and vocational training opportunities for the retarded. One board member was active in a local taxpayers' league fighting against any expansion in public expenditures. Another was sympathetic with the proposal of a large landowners' group advocating reduced property taxes and a shift to greater reliance on other sources of revenue. Also represented was a growing group of parents and teachers demanding that any new expenditures go first to sharp expansion in drug prevention programs. Whose interests would prevail? Without some shifts in influence, this situation was stalemated.

To intervene effectively in one's own community, one must understand the social forces which maintain the existing distribution of resources. Often the initial response to inquiries takes some form of "That's all our budget allows for." Humans, however, create a budget; and, if so motivated, they can change it. Hence, any examination of limitations or gaps in services must dig deeper into the influences acting upon the decision-makers who control the distribution of resources.

Such an investigation should not only identify what forces are operating to maintain the present situation, but also specify what influences would bring about the desired change in each situation and what levers could exert these influences. The persons or groups with the authority to make the needed changes must be identified. Further, the persons or groups who may control or influence these people must be recognized, as well as the nature, extent, and channels of their influence on the decision-makers. Then, the available methods can be addressed.

INVENTORY OF RESOURCES FOR INFLUENCE

Having specified what each change would require, we can then turn to an inventory of our own base or stockpile of resources for action. What of ours could influence the decisions of the group we want to change? Beginning with a careful analysis of our own group's membership or constituency, we can document the range and extent of resources accessible to us. Numerous tools of kinds of resources can overcome resistance and change a social situation. Any list of them would at least include:

1. Personal energy
2. Professional knowledge
3. Money and credit
4. Popularity and charisma
5. Political standing
6. Social standing
7. Legitimacy or legality
8. Special position for receiving and controlling the flow of information[5]

Varied social resources influence decisions in varied ways. One way to categorize the means of influence is (1) persuasion, (2) inducements, and (3) constraints.[6]

PERSUASION

Probably the most frequently used method of trying to bring about change is persuasion. Individually or in groups, advocates have approached community agencies with appeals to them to modify some aspect of their program—be it eligibility requirements, nature or extent of services, or other practices. These advocates have marshalled evidence of insufficient or inappropriate services or of unmet needs and argued to persuade the administrators or commissioners to change their agencies' policies or practices. The matter is referred to a committee for further study; the desired change is postponed indefinitely.

While rational persuasion is doubtless the easiest and least problematic method of attempting to influence decisions, it is also possibly the least effective. As a result of reasoning or facts alone, few policies change regardless of the good will with which the proposal may be presented. More subtle but more powerful influences bring about and maintain the policies and practices of community agencies, and they will respond only to equal or greater social forces.

Of course, objective information and reasoned arguments are useful and necessary tools. But when we analyze what is actually required to change a given situation, we must ask, "To what extent will persuasion help?" "With whom?" "Under what circumstances?" "What sort of approach will best accomplish our objective?"

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[5] Nelson W. Polsby, *Community Power and Political Theory*, New Haven: Yale University Press, 1963; Robert Morris and Robert H. Binstock, *Feasible Planning for Social Change*, New York: Columbia University Press, pp. 118–119.

[6] William A. Gamson, *Power and Discontent*, Homewood, Ill.: The Dorsey Press, 1968, pp. 73–81.

INDUCEMENTS

Agencies, boards, and policies exist not only for obvious reasons but also for the private goals and interests of the groups and individuals which set them up and control them. Such factors are no less real or powerful because they are not readily apparent. People conduct their activities and make decisions for a variety of rewards, from personal satisfaction or benefits to increased recognition, status, or power. For example, the elected official usually anticipates the voters' reactions to his taking one or another position on an issue. Before proposing a change, the manager of a private social agency will weigh his board members' likely reactions. A public agency's administrator must consider the positions of the members of the legislature.

An inducement offers new advantages to the decisionmaker's situation. The advocates seek to exchange some resource of theirs for the desired decision or change. Such bargains may be objectively stated or implicit, immediate or long-term. Because a certain city council candidate supports zoning variances for group homes for retarded persons, for example, one group may publicly endorse him; or the group may offer him its support if he will do so.

Many respond to the opportunity for favorable publicity. An agency may desire public credit for discovering an unmet need which it could serve or for leading the way in resolving some community problems. If a group is willing to trade leadership or public image or some other resource for the solution or change it desires, the agency may be induced to take the necessary action.

CONSTRAINTS

The reverse of advantages is disadvantages, and advocate groups may likewise consider applying undesired influences to the social situation. Imagine that a parents' association told a councilman that it would support his reelection only if he voted against a restrictive ordinance. If the councilman had always had the group's support, then such a communication would threaten him. If the group had opposed him in the past and he had no expectation of their support, the statement would promise a new advantage to him. If he had never heard of them, or if he knew they could not deliver on the promise, he would probably ignore the statement.

Most groups avoid unfavorable publicity. The threat to expose a practice of discrimination in services may suffice to bring about a change. More entrenched problems may require legislative changes, public investigations, or lawsuits. One of the outstanding examples of the skillful and effective use of adverse publicity to stimulate social change is the recent report on discrimination against retarded and emotionally disturbed children in one state's public schools.[7] Numerous examples show the use of legal action to bring about better services: such as the case of Wyatt v. Stickney in Alabama, which focused upon the right to treatment; Florida Association for Retarded Children v. State Board of Education and Case v. State of California, which focused on the right to public education; and many others.[8]

MATCHING RESOURCES TO OBJECTIVES

To make promises or threats is a hollow activity if the influencer has no control over the resources necessary to implement them. Hence, a group must carefully inventory its resources and reexamine its goals realistically in light of its actual capabilities. Possibly some situations are controlled by influences beyond reach. Some proposed changes may be so extensive that reaction would defeat the attempt. A group might have to scale down an objective or modify the scope of change to a level feasible for the resources it can actually bring to bear.

Some decision-makers may respond to certain forms or methods or amounts of influence but not to others. Hence a group must attempt to match up resources to targets carefully, seeing that inappropriate efforts do not waste or overextend its capacities, but bring them to bear efficiently.

Some objectives may require a level of influence beyond a group's immediate control. However, it can temporarily postpone direct action and invest a portion of its resources into developing a greater stock of influence for later use. For example, it may seek an alliance with another organization which is pursuing similar goals. Or, it may seek to get a key community person onto its board so as later to influence his decisions.

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[7] Task Force on Children Out of School, *Suffer the Children: The Politics of Mental Health in Massachusetts.* Boston: The Task Force, Inc., 1972.

[8] See Paul Friedman, *Mental Retardation and the Law: A Report on Current Court Cases.* Washington, D.C.: Office of Mental Retardation Coordination, D.H.E.W., July, 1973; also see the "How to Sue Package," National Association for Retarded Children, Arlington, Texas.

IMPLEMENTING AND MONITORING THE ACTION PLAN

To achieve its objectives, a group must formulate a feasible and realistic plan of action. A sequence of steps and alternatives can be designed, along with designating appropriate persons to implement each one. Tasks must account for the skills of the individuals or group and the receptivity of the target groups.

The action plan may involve several steps and influences brought to bear sequentially or simultaneously. As one writer suggests: "The actions of many persons, each of whom has independent authority, must be concerted for a proposal to be adopted; the proponents of the proposal try to concert these actions by exercising influence—by persuading . . . rewarding, punishing, and otherwise inducing; meanwhile the opponents exercise influence either to prevent the actions from being concerted or to concert them in behalf of some alternative proposal which they prefer."[9]

For us to know the extent to which our efforts are paying off, we will want to develop further methods of keeping track of the original needs and objectives of our group. Are services being opened up and brought to our group; are they available in sufficient quantity and at the needed times; are the services effective in meeting the original needs; were there unexpected consequences?

Such documentation helps us in numerous ways. Primarily, it will constitute specific evidence about which of the needs of retarded persons are being met and to what extent. Beyond this, it will provide reinforcement and satisfaction to our group to see that our efforts have paid off. Further, such evidence can be fed back publicly to the group providing the service as positive indications of their success as service providers. Finally, a system of monitoring needs and services will allow us to identify additional needs of retarded persons and thus provide an information base for formulating new objectives.[10] We can then begin anew the cycle of action and advocacy on behalf of these persons.

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[9] Edward C. Banfield, *Political Influence: A New Theory of Urban Politics*. New York: Free Press, 1968, p. 307.

In conclusion, the supportive community services needed by retarded persons are varied, and community agencies have often ignored or underserved this group. Changes will come arduously and slowly, but these situations are not impervious to appropriate influence carefully applied. Strategies for mobilizing the needed services are based upon careful analysis of the social forces to which the agencies respond and the skillful accumulation and application of such influences to appropriate points in the target agencies. Social and political resources can induce or constrain decision-making groups to allocate the services needed by retarded persons. Such carefully planned and executed advocacy efforts can result in marked changes in the availability, accessibility, and effectiveness of human services. With such increased supports, more retarded persons will benefit from human services and be able to live normal lives in our communities.

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[10] Gregory M. O'Brien, *Information Utilization in Human Service Management: The Decision Support System Approach.* National Conference on Social Welfare Forum, 1973. New York: Columbia University Press, forthcoming.

SUMMARY

SUMMARY

by Ruth Freedman

A mentally retarded citizen searching for a home must explore beyond a simple structure. A physical abode itself does not assure successful and fulfilling community living. As Lotte Moise has described, a house in the community must first of all be a home. But a mentally retarded citizen must search for a *community* as well as a *home*—a community which accepts him as a fellow human being and which offers him the same opportunities, responsibilities, and risks offered to all citizens. This monograph has examined some of the essential characteristics in homes and communities which enable all persons to live as human beings. This final chapter will summarize some of the principles and goals set forth in this monograph and will then look at the role of mentally retarded citizens in determining where and how they shall live.

FUNDAMENTAL PRINCIPLES

Basic to all chapters, certain fundamental principles evidence this monograph's philosophy.

- The mentally retarded person can grow and change. The status of being retarded is open to change as is the level or degree of mental retardation. All persons have potential for development; the label and effects of mental retardation are not irreversible.
- A mentally retarded person's needs change as he grows and develops. Transitions from childhood to adolescence, to adulthood, and to old age are natural for all persons; and needs change at each stage.
- The needs of mentally retarded persons differ from individual to individual. Retarded persons, like all persons, have unique abilities and disabilities, likes, and dislikes. Each person grows, develops, and ages according to his own individual pattern; his needs reflect his uniqueness.
- All persons share certain universal needs. We all strive to meet our common needs for shelter, health, physical development, and personal and social growth. Disabled

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persons' needs differ only in their capabilities to meet these needs.

- All persons are entitled to certain human and civil rights. The rights to due process, to education, and to a life in the community have recently been in the forefront of the civil rights field. In addition, society takes for granted human rights to which even the most profoundly disabled persons are entitled—the right to respect, to dignity, to responsibility, to risk taking, and to individual life styles. These rights enable the mentally retarded individual to live as independent a life as is possible.

GOALS FOR A SYSTEM OF SERVICES

This monograph has attempted to translate the fundamental principles into goals for a system of services designed to meet the needs of mentally retarded persons. Some of the goals which have been emphasized include the following:

- Mentally retarded persons should receive generic services wherever possible. A system need not isolate the human needs of mentally retarded persons from the universal needs of all other persons.
- The system should provide a *continuum* of services, ranging from prevention programs to services for infants, children, adolescents, adults, and aging adults. Services should conform to the changing needs of mentally retarded persons and their families at these different stages of life.
- Services should be geared toward persons with *varying levels of capability*. No single service will meet the needs and abilities of all mentally retarded persons. In designing community residences, in particular, no one model will benefit everyone. There should be specialized community facilities for persons with severe disabilities, independent apartment units with little or no supervision for persons with minor disabilities, and a variety of living arrangements for persons between these two extremes. Similarly, at work, some individuals may require sheltered workshop settings, while others may be able to work in competitive employment settings.
- Services should be *individualized*. They should meet the needs of individuals, not the needs of a class of persons or the needs of the service system itself. Appropriate

diagnosis and ongoing evaluation, individual treatment plans, and periodic review procedures can help to assure individualization.

- Services should be provided in a manner consistent with the *civil and human rights* shared by all citizens—the rights to dignity, respect, fair procedures, and equal protection under the law.
- Services should strive to *integrate* clients into the mainstream of community life. Services should promote and ensure the participation of mentally retarded persons in normal community activities: educational, vocational, social, recreational, and religious.
- Services should be *dispersed* geographically so that they are available to all. In urban areas, this requires placing services in areas convenient to the users, accessible by public and private transportation. In rural areas, where distances between population centers are great, transportation is a crucial factor. Either the client must go to the service or the service must come to the client.
- When necessary, the system should provide the transportation. Services must generate *community awareness* and *support*. Outreach models must be developed which inform community members of available resources and programs. Public education and legislative campaigns must be mounted to generate support for community programs for mentally retarded citizens.
- Services must be *accountable* to the clients. Providers of services must be continually monitored to ensure that they are meeting the needs of their clients. Associations and volunteer and advocacy groups can monitor and evaluate the overall service network to determine gaps in services and to press for the elimination of these inadequacies.

NEW DIRECTIONS

This monograph has discussed the philosophy, goals, and characteristics of community services for mentally retarded citizens. The authors do not presume, however, that the principles set forth here are permanent. Rather, we anticipate that new principles, goals and methods will emerge as the needs of mentally retarded persons in the community evolve. Evidently, mentally retarded persons will formulate and promote some of these new features. Too often we tend to view these citizens as the objects of services, rather than as primary actors in determining the kinds of services they need.

In this community movement retarded citizens must have a say about which services are developed and how they are delivered. Their voices can clarify planning and aid service delivery. And even more importantly, to deny them meaningful participation is to devalue them as human beings. As Ann Shearer has stated:

> If participation is to develop strongly it requires all of us to see 'mentally handicapped' people as equal human beings to the rest of society; with a positive contribution to make to that society; who need and are entitled to be listened to; who receive services as a right because of their citizenship in our society and not from a sense of charity for lesser beings; who like everyone else respond to the way they are treated; and who have a right to respect. Only in these circumstances with these conditions accepted, does participation become an important, indeed an essential element of services, because it is only in these circumstances that recipients and providers of services can come together in a way that ensures participation.[1]

Participation of mentally retarded persons in decision making is not merely a forecast for the future. Already, we are witnessing the beginning stages of this movement. Both in this country and in others, mentally retarded persons have come together to voice their concerns and to organize support. Since 1968, the Swedish Association for Retarded Children has sponsored a series of conferences for young mentally retarded adults. At one of these meetings in 1970, the participants themselves drew up a position paper which expressed their concerns about leisure-time activities, vacation, living conditions, education, employment, and wages. Although the document is too lengthy to present in its entirety here, the following excerpt on "living conditions" shows the types of conclusions which were reached.

> *Living Conditions:*
>
> *We wish to have an apartment of our own and not be coddled by personnel; therefore we want courses in cooking, budgeting, etc.*
>
> *We want to have a right to our own apartment but without priority on the waiting list (In Sweden, one may have to sign up for an apartment well in advance).*

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[1] Ann Shearer, *Listen* (London: Campaign for the Mentally Handicapped, 1973).

> *We want the right to move together with the other sex when we feel ready for it, and we also want the right to marry when we ourselves find the time is right.*
>
> *We who live in institutions and boarding homes have found that:*
>
> > *The homes should be small.*
> > *We want to choose our own furniture, and have our own furniture in the room.*
> > *We will absolutely not have specific hours to follow in terms of going out, returning, etc.*
>
> *We want to have more personal freedom, and not as it is now in certain institutions and boarding homes where you have to ask permission to shop for fruit, newspapers, tobacco, etc.*
>
> *We want the right to invite other youngsters to our hostels.*
>
> *One should not have food coupons in institutions and hostels even if it has practical advantages; we want to pay with our own money.*
>
> *When we are living in institutions, we want social training to be able to move out into society and manage on our own. Even in institutions, we want to be able to go steady and live together with the other sex without having the personnel interfering with our private lives.*
>
> *We who live at home have found that:*
>
> > *It is largely good, but one ought to move out when the time is right to a service sheltered apartment or hostel; one cannot for his whole life be dependent on his parents. We want, however, to have our own key when we live at home.*[2]

Similarly, in Britain, two major conferences have been held for and with mentally retarded persons, sponsored by the Campaign for the Mentally Handicapped. In 1973, providers of services as well as consumers attended LISTEN, the second conference. The purpose of LISTEN was to give the mentally retarded consumers an opportunity to present their views on needed services. In the discussions held on living, working, and leisure—the need for choice, independence, and participation emerged as the major themes. Conference participants hoped that such meetings would pave the way for more direct involvement of consumers in the planning and development of services.

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[2] Bengt Nirje, "*Report on a Conference of Retarded Young Adults in Malmo,*" 1968. (Mimeographed.)

In the United States, mentally retarded citizens have also organized on their own behalf. Several state conventions for mentally retarded adults have met, for example in Massachusetts and Rhode Island, in which delegates have discussed such issues as dehumanization and restriction of civil rights. Mentally retarded persons have also formed advocacy groups to provide public education to community groups and consultation to agencies planning and providing community services.

The formation of these self-advocacy groups suggests that consumer participation may soon be strengthened. Without meaningful opportunities for this participation, mentally retarded persons lack full citizenship. After spending 25 years in the institution and now pushing for community placement, one resident of a Massachusetts state school said:

> *I want to be a citizen. I want to do what every citizen can do. Citizenship means voting. Citizenship means working, it means helping others. It also means that we are able to make important decisions for ourselves. Our families and the people who work with us can help us, but if citizenship is to mean anything we must make the final decision.*

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